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ORIGINAL RESEARCH

Participation, characteristics and retention rates of HIV-positive immigrants in the Swiss HIV Cohort Study*

C Thierfelder,[1] R Weber,[1] L Elzi,[2] H Furrer,[3] M Cavassini,[4] A Calmy,[5] E Bernasconi,[6] C Gutmann,[7] B Ledergerber[1] and the Swiss HIV Cohort Study Group

[1]Division of Infectious Diseases and Hospital Epidemiology, University Hospital Zurich, University of Zurich, Zurich, Switzerland, [2]Division of Infectious Diseases and Hospital Epidemiology, University Hospital Basel, Basel, Switzerland, [3]Clinic for Infectious Diseases, Bern University Hospital and University of Bern, Bern, Switzerland, [4]University Hospital Lausanne, Lausanne, Switzerland, [5]University Hospital Geneva, Geneva, Switzerland, [6]Regional Hospital Lugano, Lugano, Switzerland and [7]Catonal Hospital St Gallen, St Gallen, Switzerland

Objective

Data from observational cohorts may be influenced by population structure and loss to follow-up (LTFU). Quality of care may be associated with participation in cohort networks. We aimed to study the participation, characteristics and retention rates of immigrants in the Swiss HIV Cohort Study (SHCS).

Methods

We compared enrolment over time (1996–1999, 2000–2003 and 2004–2008) and LTFU between individuals from different geographical regions. In 2008, we performed a cross-sectional survey to investigate the proportion of individuals not participating in the SHCS but who were in care at SHCS institutions. Predictors for LTFU were analysed using Cox proportional hazard models, and those for nonparticipation using logistic regression.

Results

A total of 7840 individuals entered the SHCS during the observation period. The proportion of immigrants increased over time, especially the proportion of women from sub-Saharan Africa, which increased from 21 to 48% during the observation period. Overall LTFU was 3.76 [95% confidence interval (CI) 3.58–3.95]/100, with the highest hazard ratio in men from sub-Saharan Africa (2.82/100 patient-years; 95% CI 2.30–3.46/100), compared with men from northwestern countries. Other predictors for LTFU were age <30 years, lower education, injecting drug use, and higher baseline CD4 cell counts. Participants taking antiretroviral therapy had reduced LTFU. The survey showed that 84% of HIV-infected patients in care at SHCS institutions were enrolled in the cohort. Nonparticipation was more likely among men from non-European regions (odds ratio 2.73; 95% CI 2.29–3.24), women from sub-Saharan Africa (odds ratio 3.01; 95% CI 2.40–3.77) and women from Latin America/Caribbean (odds ratio 2.10; 95% CI 1.30–3.39).

Conclusions

Numbers of HIV-infected immigrants are increasing but they are underrepresented in the SHCS, and immigrants are more likely to be lost to follow-up.

Keywords: cohort study, gender, HIV infection, immigrants, loss to follow-up, participation, sub-Saharan Africa

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*See Appendix.

Correspondence: Dr Bruno Ledergerber, Division of Infectious Diseases and Hospital Epidemiology, University Hospital Zurich, Ramistrasse 100, CH-8091 Zurich, Switzerland. Tel: + 41 44 255 33 57; fax: + 41 44 255 44 99; e-mail: infled@usz.uzh.ch

Introduction

World-wide, there are an estimated 214 million international migrants, comprising 3.1% of the global population [1]. Migrants and mobile people are increasingly recognized

as more vulnerable to HIV/AIDS than resident populations. They may also face greater obstacles in accessing medical care and social support, particularly if living with HIV or AIDS [2]. Currently, 22% of people living in Switzerland are foreign-born, with the percentage varying regionally and reaching up to 38% in the French-speaking urban areas of the country [3]. The majority of HIV-positive migrants from high-prevalence countries were infected in their home regions [4,5].

In Switzerland, the HIV epidemic mainly affected men who have sex with men (MSM) and injecting drug users (IDUs) in the 1980s. Since 1995, heterosexual contact has been the most frequent mode of HIV transmission (40% of all infections), and this has also been the case among immigrants. Data from the Swiss Federal Office of Public Health [6] and the Swiss HIV Cohort Study (SHCS) showed an increasing number of HIV-positive immigrants from high-prevalence countries at the beginning of the 21st Century [3,7].

HIV-positive persons with regular and unrestricted access to care have better health outcomes [8]. Between 70 000 and 180 000 undocumented immigrants are estimated to live in Switzerland [6]. Health insurance is compulsory and defined as a right for all residents, including undocumented people, in Switzerland. However, more than 90% of the undocumented migrants are estimated to have no health insurance [9].

Data from European HIV-infected cohorts indicate that migrants are prone to loss to follow-up (LTFU) [10,11], which may lead to loss of statistical power, bias in study results and lack of generalizability of study findings [12]. In contrast to other observational databases [11,13], the SHCS requires written informed consent which may pose a barrier to participation.

LTFU and participation have not been studied in previous research on immigrants in the SHCS [4,7]. Therefore, we aimed to study (i) the demographic and clinical characteristics, (ii) the time trends and (iii) the retention rates of cohort participants of different geographical origins. Furthermore, we quantified nonparticipation in the SHCS by means of a cross-sectional survey.

Methods

Cohort study

The SHCS was established in 1988 (www.shcs.ch) as a collaboration of seven specialized centres [14]. Since 1995, interested private physicians and regional hospitals have also collaborated. In 2008, 32% of SHCS participants were treated by private physicians. The study has been approved by local ethical committees and written informed consent is obtained from all participants. For this study, we selected all participants who entered the SHCS between 1 January 1996 and 31 December 2008.

Survey on nonparticipation in the cohort

The seven SHCS centres, 13 affiliated hospitals and 33 private collaborating physicians from all regions of the country were addressed in formal correspondence to provide aggregated (i.e. unidentifiable) numbers of HIV-positive persons not participating in the SHCS during their first clinical visit in 2008. Collected information included geographical region of origin, gender, injecting drug use (IDU) and whether the patient was on ART. After two rounds of reminders via email and/or telephone, the response rate was 40 of 53 (75%) clinics or private physicians, and those that responded included all seven SHCS centres and all large institutions providing HIV care.

Definitions

Among participants not known to have died, we defined LTFU as no further cohort visit during at least 1 year after the last visit.

We distinguished seven geographical regions of patients' origin according to an adopted UNAIDS classification of nationalities [15]. Because of the small numbers of persons in care and their similar demographic characteristics, we merged the Caribbean and Latin America into one region and combined the USA, Canada, Australia and New Zealand with northwestern Europe. Thus, the regions were: (1) Northwestern countries (Switzerland, Andorra, Austria, Belgium, Denmark, Finland, France, Germany, the UK, Iceland, Ireland, Liechtenstein, Luxemburg, Monaco, the Netherlands, Norway, Sweden, USA, Canada, Australia and New Zealand); (2) sub-Saharan Africa; (3) Southern Europe (Spain, Portugal, Italy, Greece, Malta and San Marino); (4) Latin America/Caribbean; (5) Southeastern Asia; (6) Eastern Europe/Central Asia; and (7) Northern Africa/Middle East.

The SHCS collects information on ethnicity, categorized as White, Black, Asian and Hispano-American. Because there was a congruent picture between nationality and ethnicity in five out of the seven regions described above ($>96\%$ of participants), we did not analyse the data for ethnicity separately.

Data analyses

Demographic and clinical characteristics at inclusion were analysed for three calendar periods (1996–1999, 2000–2003 and 2004–2008) to determine trends over time. Cox proportional hazards models were fitted to examine the effects of region of origin, gender, age, education, IDU, clinical HIV disease stage and treatment status on the probability of ceasing to participate in the SHCS. CD4 cell count was also fitted as a time-updated covariable. Because

Table 1 Demographic and clinical characteristics of 7840 individuals at enrolment in the Swiss HIV Cohort Study (SHCS) from 1996 to 2008 by region of origin

	Northwestern countries	Sub-Saharan Africa	Southern Europe	Latin America/ Caribbean	Southeastern Asia	Eastern Europe/ Central Asia	Northern Africa/ Middle East	P*	Total
No. of SHCS participants	5283	1103	622	306	251	174	101		7840
Age (years) [median (IQR)]	38 (32–45)	32 (27–37)	36 (31–43)	34 (29–38)	32 (27–37)	34 (28–43)	34 (27–42)	<0.001	36 (30–43)
Female [*n* (%)]	1256 (24)	728 (66)	104 (17)	117 (38)	151 (60)	48 (28)	24 (24)	<0.001	2428 (31)
HIV transmission risk [*n* (%)]								<0.001	
Heterosexual	1650 (31)	988 (89)	216 (35)	139 (46)	153 (61)	87 (50)	61 (60)		3294 (42)
Homo-/bisexual	2315 (44)	22 (2)	211 (34)	143 (47)	70 (28)	49 (28)	20 (20)		2830 (36)
Injecting drug use	1121 (21)	11 (1)	172 (28)	10 (3)	10 (4)	32 (18)	12 (13)		1368 (18)
Other	197 (4)	82 (8)	23 (4)	14 (5)	18 (7)	6 (4)	8 (8)		348 (4)
Completed mandatory school [*n* (%)]	5055 (96)	845 (77)	559 (90)	271 (88)	178 (71)	149 (86)	86 (85)	<0.001	7143 (91)
Time HIV-positive (months) [median (!QR)]	5.8 (0.8–63)	4.4 (0.8–17.4)	6.2 (0.9–62.3)	5.4 (0.9–32.4)	3.8 (0.6–17.7)	3.1 (0.7–16.8)	2.4 (0.6–30.4)	<0.001	5.3 (0.8–48.7)
On antiretroviral treatment [*n* (%)]	1410 (27)	449 (41)	196 (32)	101 (33)	85 (34)	44 (25)	27 (27)	<0.001	2312 (30)
CD4 count (cells/μL) [median (IQR)]	350 (188–545)	304 (190–462)	328 (166–541)	370 (204–517)	243 (103–382)	350 (204–500)	360 (195–560)	<0.001	339 (185–526)
CD4 count <350 cells/μL [*n* (%)]	2641 (50)	643 (58)	327 (53)	145 (47)	171 (68)	86 (49)	46 (46)	<0.001	4059 (52)
HCV antibody positive† [*n* (%)]	1285 (25)	40 (4)	194 (32)	18 (6)	20 (8)	41 (24)	18 (18)	<0.001	1616 (21)
Active hepatitis B virus infection‡ [*n* (%)]	204 (3.9)	99 (9.1)	34 (6.4)	9 (3.0)	26 (10.4)	10 (5.8)	3 (3.0)	<0.001	391 (5.0)
Syphilis§ [*n* (%)]	431 (8.2)	102 (9.2)	53 (8.5)	61 (19.9)	24 (9.5)	14 (8.0)	11 (10.8)	<0.001	696 (8.9)
Clinical CDC stage C¶ [*n* (%)]	792 (15)	187 (17)	95 (15)	43 (14)	49 (20)	23 (13)	15 (15)	0.31	1204 (15)
Tuberculosis [*n* (%)]	52 (1.0)	80 (7.3)	10 (1.6)	4 (1.3)	8 (3.2)	2 (1.2)	4 (4.0)	<0.001	160 (2.0)
Pneumocystis jiroveci pneumonia [*n* (%)]	345 (6.5)	27 (2.5)	33 (5.2)	16 (5.2)	21 (8.4)	4 (2.3)	4 (4.0)	<0.001	450 (6.0)
Candida oesophagitis [*n* (%)]	202 (3.8)	27 (2.5)	29 (4.7)	10 (3.3)	9 (3.6)	4 (2.3)	4 (4.0)	0.25	285 (4.0)
Cerebral toxoplasmosis [*n* (%)]	83 (1.6)	19 (1.7)	11 (1.8)	9 (2.9)	4 (1.6)	1 (0.6)	0 (0.0)	0.38	127 (1.6)
Cerebral cryptococcosis [*n* (%)]	6 (0.1)	2 (0.2)	0 (0.0)	0 (0.0)	4 (1.6)	0 (0.0)	1 (1.0)	<0.001	13 (0.2)
Kaposi's sarcoma [*n* (%)]	142 (2.7)	15 (1.4)	15 (2.4)	3 (1.0)	0 (0.0)	7 (4.0)	1 (1.0)	0.004	183 (2.3)

CDC, Centers for Disease Control and Prevention; IQR, interquartile range.
*P-values are for χ^2 and Kruskal–Wallis tests for differences across regions.
†Missing HCV serology for 238 individuals.
‡Hepatitis B virus surface (HBs) antigen or hepatitis B virus DNA positive; missing information for 73 individuals.
§TPPH or TPHA positive; missing information for 302 individuals.
¶One patient may have contributed to multiple diseases.

of evidence of an interaction [likelihood ratio test (LRT) $P<0.001$] between region of origin and gender, we analysed the risk for LTFU separately for women and men.

Data from the survey on SHCS participation were analysed using logistic regression. Because the group of former participants was very small (3.7%), we decided to exclude them from the analysis and compare current participants *vs.* never participants. Because of evidence of an interaction between region of origin and gender (LRT $P=0.016$), we calculated the odds of nonparticipation separately for men and women. Analyses were carried out using Stata software (version 11.2; StataCorp LP, College Station, TX, USA).

Results

Baseline demographic characteristics of SHCS participants

Between 1996 and 2008, 7840 participants were enrolled in the SHCS. Table 1 shows baseline characteristics stratified for region of origin: 67% of participants originated from northwestern regions, 14% from sub-Saharan Africa, 8% from southern Europe, 4% from Latin America/Caribbean, 3% from southeastern Asia, 2% from eastern Europe/Central Asia and 1% from northern Africa/Middle East. The gender composition varied considerably among the immigrant groups included. The proportion of women ranged from 17% in participants from southern Europe to 66% in participants from sub-Saharan Africa. Similarly, heterosexual transmission ranged from 31% in northwestern countries to 89% in sub-Saharan Africa. IDU as a mode of HIV acquisition was 28% in southern Europe, 22% in northwestern countries and 4, 3 and 1% in participants from southern Europe, Latin America/Caribbean and sub-Saharan Africa, respectively. Persons from sub-Saharan Africa and southeastern Asia were less likely to have completed mandatory school as compared with groups of other origin.

Participants from sub-Saharan Africa, southeastern Asia and eastern Europe/Central Asia showed a proportional increase in enrolment into the SHCS over time, while the

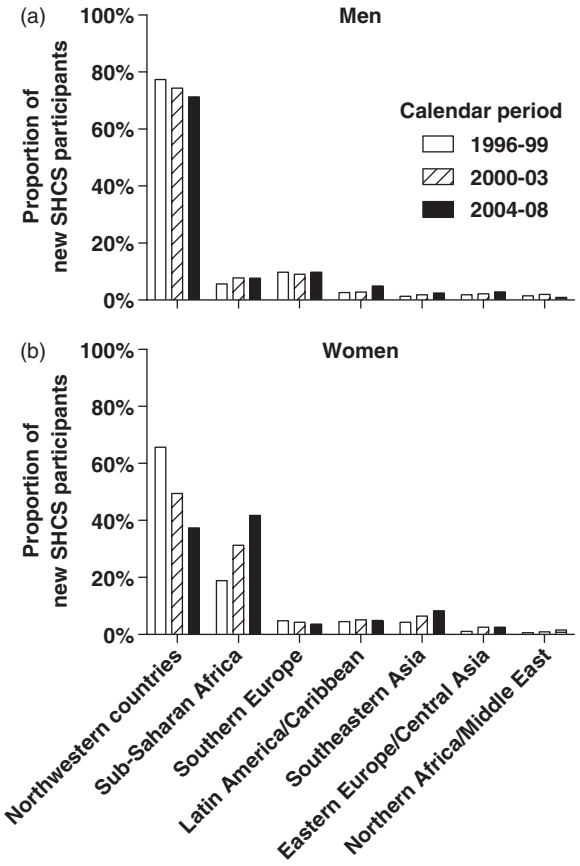

Fig. 1 Enrolment of Swiss HIV Cohort Study (SHCS) participants over time by geographical region of origin and sex.

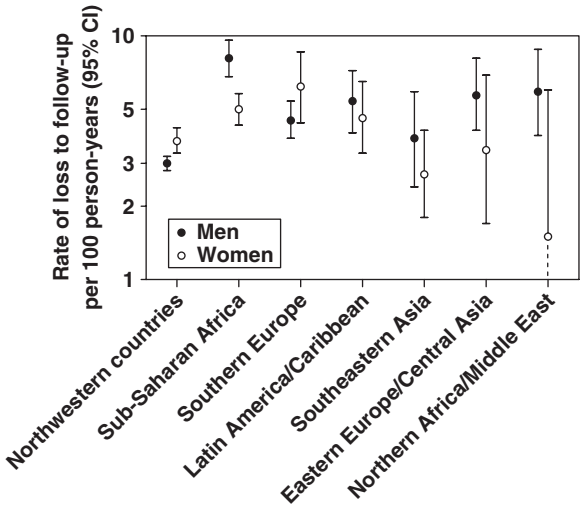

Fig. 2 Rates of loss to follow-up by geographical region of origin and sex. CI, confidence interval.

proportion of groups of other origin decreased. The most striking rise occurred in women from sub-Saharan Africa: in the last observation period, women from sub-Saharan Africa presented the largest group of all new enrollees (increasing from 19 to 42%). In men from sub-Saharan Africa, the increase was smaller (5.6 to 7.7%). Also in participants from southeastern Asia the increase in enrolment was more pronounced in women than in men, almost doubling from 1996–1999 to 2004–2008 (Fig. 1).

Clinical characteristics

On average, persons from sub-Saharan Africa, southern Europe and southeastern Asia enrolled with more advanced HIV infections than those from northwestern countries (Table 1). The most common opportunistic infection (OI) was *Pneumocystis jiroveci* pneumonia, which occurred in 6% of all participants. A history of tuberculosis (TB) was present in 2% of study participants; in 1% of those from northwestern countries and in 7% of those from sub-Saharan Africa. Participants from sub-Saharan Africa and southeastern Asia had the highest prevalence of active hepatitis B virus infection (9 and 10%, respectively). Serological evidence of past or present syphilis was found in 20% of participants from Latin America/Caribbean.

Retention in the cohort

A total of 1635 (20.9%) participants were lost to follow-up. The rate of LTFU was 3.76 [95% confidence interval (CI) 3.58–3.95]/100 person-years (py), ranging from 3.19 (95% CI 2.99–3.39)/100 py in participants from northwestern countries to 6.03 (95% CI 5.40–6.74)/100 py in participants from sub-Saharan Africa. Among participants from European countries, women were more likely to be lost to follow-up; in non-Europeans, men were more likely to be lost (Fig. 2). Of all subgroups, men from sub-Saharan Africa had the highest rate of LTFU, at 8.10 (95% CI 6.83–9.56)/100 py, a significantly higher rate than that for sub-Saharan Africa women, at 5.04 (95% CI 4.34–5.84)/100 py.

As shown in Table 2, all male migrant groups, with the exception of men from southern Europe, had a higher hazard of LTFU compared with those from northwestern regions; African men had the greatest hazard. In women, immigrants from sub-Saharan Africa, southern Europe and Latin America/Caribbean were more likely to be lost to follow-up. In both men and women, younger patients, and patients with less education, IDU and a higher CD4 cell count at baseline were more prone to LTFU. In contrast, in the time-updated analysis, participants with a higher latest CD4 cell count were less likely to be lost to follow-up:

Table 2 Uni- and multivariable Cox regression models assessing the hazard of loss to follow-up; 7840 Swiss HIV Cohort Study (SHCS) participants experienced 1635 events

	Men						Women					
	Crude hazard ratio	95% CI	*P*	Adjusted hazard ratio*	95% CI	*P*	Crude hazard ratio	95% CI	*P*	Adjusted hazard ratio*	95% CI	*P*
Region												
Northwestern regions	1	Reference		1	Reference		1	Reference		1	Reference	
Sub-Saharan Africa	2.61	2.17–3.14	<0.001	2.82	2.30–3.46	<0.001	1.31	1.09–1.58	0.005	1.62	1.29–2.04	<0.001
Southern Europe	1.51	1.25–1.83	<0.001	1.34	1.10–1.63	0.003	1.62	1.14–2.32	0.007	1.42	0.99–2.03	0.054
Latin America/Caribbean	1.77	1.30–2.40	<0.001	1.85	1.35–2.53	<0.001	1.22	0.84–1.75	0.293	1.46	0.99–2.14	0.051
Southeastern Asia	1.25	0.79–1.96	0.346	1.29	0.81–2.06	0.280	0.71	0.45–1.10	0.127	0.82	0.51–1.31	0.410
Eastern Europe/Central Asia	1.89	1.34–2.69	<0.001	1.75	1.23–2.50	0.002	0.88	0.44–1.78	0.728	0.96	0.47–1.95	0.912
Northern Africa/Middle East	1.93	1.29–2.90	0.002	1.81	1.20–2.73	0.005	0.40	0.01–1.60	0.196	0.44	0.11–1.79	0.254
Age												
>50 years	1	Reference		1	Reference		1	Reference		1	Reference	
30–49 years	1.47	1.20–1.80	<0.001	1.12	0.91–1.38	0.293	1.63	1.06–2.52	0.026	1.22	0.78–1.89	0.379
<30 years	2.02	1.60–2.54	<0.001	1.25	0.98–1.60	0.069	2.20	1.42–3.41	<0.001	1.48	0.94–2.33	0.091
Education												
Professional education	1	Reference		1	Reference		1	Reference		1	Reference	
Mandatory education	1.71	1.47–1.98	<0.001	1.23	1.04–1.44	0.014	1.38	1.15–1.66	0.001	1.23	1.02–1.50	0.029
School not completed	1.97	1.60–2.41	<0.001	1.26	1.01–1.56	0.038	1.50	1.20–1.88	<0.001	1.34	1.06–1.70	0.013
Injecting drug use	1.89	1.66–2.16	<0.001	1.98	1.71–2.30	<0.001	1.73	1.44–2.06	<0.001	2.04	1.64–2.54	<0.001
On ART at baseline	0.82	0.73–0.93	0.002	0.84	0.74–0.95	0.006	0.83	0.60–1-16	0.275	0.89	0.75–1.05	0.175
CDC stage C at baseline†	0.88	0.74–1.04	0.121				0.79	0.60–1.03	0.092			
CD4 count at baseline												
<200 cells/μL	1	Reference		1	Reference		1	Reference		1	Reference	
200–349 cells/μL	0.99	0.84–1.18	1.000	0.99	0.84–1.17	0.912	1.40	1.10–1.78	0.006	1.40	1.10–1.79	0.006
≥350 cells/μL	1.16	1.00–1.33	0.045	1.18	1.02–1.36	0.026	1.50	1.21–1.86	<0.001	1.52	1.22–1.89	<0.001
CD4 count time-updated												
<200 cells/μL	1	Reference		1	Reference		1	Reference		1	Reference	
200–349 cells/μL	0.70	0.58–0.85	<0.001	0.73	0.60–0.89	0.002	0.75	0.57–0.98	0.041	0.76	0.58–1.00	0.051
≥350 cells/μL	0.57	0.48–0.67	<0.001	0.63	0.53–0.74	<0.001	0.61	0.48–0.78	<0.001	0.64	0.50–0.82	<0.001

CDC, Centers for Disease Control and Prevention; CI, confidence interval.
*Adjusted for region, age, education, injecting drug use, on antiretroviral therapy (ART) at baseline and CD4 count at baseline.
†Not included in the multivariable model because of collinearity with CD4 count and treatment status.

hazard ratios (HRs) were 0.63 (95% CI 0.53–0.74) in men and 0.64 (95% CI 0.50–0.82) in women. Being on ART at baseline was associated with a lower risk of LTFU. Neither calendar year nor period was associated with LTFU (all $P > 0.05$; data not shown).

Cross-sectional survey on SHCS participation at cohort institutions

The survey showed that 7424 of 8802 patients (84%) receiving care at institutions of the SHCS network during 2008 were participating in the SHCS. The distribution of geographical region of origin according to cohort status is depicted in Table 3. Nonparticipation (i.e. formerly participating and never having participated in the SHCS) was highest among individuals from sub-Saharan Africa (374 of 1186; 32%), followed by northern Africa/Middle East (28 of 109; 26%), Latin America/Caribbean (74 of 329; 22%), eastern Europe/Central Asia (40 of 182; 22%), southeastern Asia (52 of 283; 18%), northwestern regions (733 of 6054; 12%) and southern Europe (77 of 659; 12%) ($P < 0.001$). More than half of all former SHCS participants (54%) had been infected via IDU. The proportion of women was higher in those who had never participated (43%) and former participants (42%) than in current SHCS participants (30%).

The proportion of individuals taking ART ranged from 69% in those who had never participated, to 77% in former participants, to 80% in current SHCS participants. In logistic regression models, men from non-European countries were less likely to participate in the SHCS than Europeans [odds ratio (OR) 2.73; 95% CI 2.29–3.24]. ORs for nonparticipation ranged from 2.80 (95% CI 1.73–4.51) for individuals from southeastern Asia, to 5.31 (95% CI 4.14–6.82) for individuals from sub-Saharan Africa. Women from sub-Saharan Africa (OR 3.01; 95% CI 2.40–3.77) and Latin America/Caribbean (OR 2.10; 95% CI 1.30–3.39) were significantly less likely to participate than those from northwestern regions. IDUs were less likely to participate in the SHCS (OR 2.19; 95% CI 1.81–2.64) while receiving ART was significantly associated with SHCS participation (OR 1.83; 95% CI 1.59–2.11).

Table 3 Cohort participation: results from the cross-sectional survey of HIV-positive persons seen at least once during 2008 at Swiss HIV Cohort Study (SHCS) clinics or by private physicians collaborating with the SHCS

Participation status/characteristic	Northwestern countries	Sub-Saharan Africa	Southern Europe	Latin America/ Caribbean	Southeastern Asia	Eastern Europe/ Central Asia	Northern Africa/ Middle East	*P*-value	Total
Current cohort participants	5321 (72)*	812 (11)	582 (8)	255 (3)	231 (3)	142 (2)	81 (1)		7424 (100)
Male	4030 (76)	247 (30)	479 (82)	165 (65)	93 (40)	95 (67)	57 (70)		5166 (70)
Female	1291 (24)	565 (70)	103 (18)	90 (35)	138 (60)	47 (33)	24 (30)	<0.001†	2258 (30)
Injecting drug use	1065 (20)	7 (1)	147 (25)	8 (3)	9 (4)	20 (14)	6 (7)	<0.001†	1262 (17)
On ART	4291 (81)	640 (79)	476 (82)	192 (75)	187 (81)	99 (70)	58 (72)	0.003†	5943 (80)
Former cohort participants	228 (71)	47 (15)	19 (6)	11 (4)	9 (3)	6 (2)	3 (1)		323 (100)
Male	142 (63)	17 (36)	13 (68)	5 (45)	5 (56)	5 (83)	2 (66)		189 (58)
Female	86 (37)	30 (64)	6 (32)	6 (55)	4 (44)	1 (17)	1 (33)	0.028†	134 (42)
Injecting drug use‡	121 (54)		11 (58)					0.72†	
On ART	177 (78)	33 (70)	16 (84)	8 (73)	6 (67)	5 (83)	3 (100)	0.75†	248 (77)
Never cohort participants	505 (48)	327 (31)	58 (6)	63 (6)	43 (4)	34 (3)	25 (2)		1055 (100)
Male	341 (68)	111 (34)	49 (85)	39 (62)	22 (51)	23 (68)	18 (72)		603 (57)
Female	164 (32)	216 (66)	9 (16)	24 (38)	21 (49)	11 (32)	7 (28)	<0.001†	452 (43)
Injecting drug use‡	150 (30)		21 (38)					0.22†	
On ART	335 (66)	240 (73)	40 (69)	45 (72)	28 (65)	17 (50)	19 (76)	0.080†	724 (69)
Total	6054 (69)	1186 (14)	659 (7)	329 (4)	283 (3)	182 (2)	109 (1)	<0.001§	8802 (100)

ART, antiretroviral therapy.
*Values are *n* (%).
‡In the survey, this information was only collected for participants from Northern/Western Europe and Southern Europe.
†*P*-value for χ^2 test of patient characteristic across region.
§*P*-value from χ^2 test of participation status across region.

Discussion

Immigrants present a substantial and rising proportion of participants in the SHCS. In the present study from 1996 to 2008, 30% of cohort participants originated from non-European countries, with more than half being from sub-Saharan Africa. In women, immigrants accounted for >60% of all enrollees in the last calendar period (2004–2008). Migrants are underrepresented in the SHCS in a double sense: they are less likely to participate in the study, and more likely to be lost to follow-up from the cohort. People from sub-Saharan Africa are most underrepresented in these ways.

A previous study from the SHCS showed a steady increase in sub-Saharan Africa participants, from 3% (1989–1992) to 12% (1997–2001) [7]. In the present study, we observed a continuation of this trend to 14% (2004–2008). The increase in the proportion of female enrollees in the SHCS was striking: the proportion of individuals from sub-Saharan Africa among women entering the SHCS rose from 19% (1996–1999) to 42% (2004–2008), thus more than doubling. The large proportion of individuals from sub-Saharan Africa among immigrants is not a reflection of a large sub-Saharan African population in Switzerland – they account for only 0.9% of 7.6 million inhabitants of the country [5] – but rather shows the high prevalence of HIV/AIDS in their countries of origin. An increasing proportion of individuals from sub-Saharan Africa in those acquiring HIV infection via heterosexual transmission has also been reported in other European countries: in the UK, more than two-thirds of newly detected HIV infections were among sub-Saharan Africans [16].

Immigrants in the SHCS were younger and had received less education than the local population, findings also reported from Spain [17,18]. People from low-income countries were found to be at increased risk of presenting with AIDS compared with HIV-positive individuals from developed countries [19]. In our study, patients from southeastern Asia enrolled with the most advanced stage of HIV infection. While there is evidence of an increased risk of sub-Saharan Africans presenting late [20,21], there is less awareness of the risk of seropositivity in southeastern Asia migrants [22]. TB as an AIDS-defining infection was found to be most prevalent in sub-Saharan Africa, reflecting the high prevalence of HIV/TB coinfections in African countries, where more than 30% of all new TB cases in adults are estimated to be associated with HIV infection [23]. Hepatitis C virus (HCV) seropositivity correlated with HIV transmission via IDU, and was thus more prevalent in northwestern countries, southern Europe and eastern Europe/Central Asia [24]. Chronic hepatitis B virus (HBV) infection was significantly more prevalent in those from sub-Saharan Africa and southeastern Asia, reflecting the geographical regions with the highest prevalence of HBV infection worldwide [25]. Past or present syphilis was disproportionally high among those from Latin America/Caribbean, a finding in accordance with surveillance data from England [26].

While retaining HIV-infected patients in medical care has been shown to be associated with improved health

outcomes, data from industrial [8] and developing countries [27] have shown that there are difficulties in patient retention. In our study, the rate of LTFU was 3.76 (95% CI 3.58–3.95)/100 py, which is similar to the 3.72 (95% CI 3.58–3.86)/100 py reported by the EuroSIDA study group [10]. In the SHCS, people originating from regions other than northwestern countries were at risk for LTFU, as shown in the French Hospital Database [11]. Although demographically similar to southeastern Asians, in the present study sub-Saharan Africans had a disproportionally high LTFU. In research on sub-Saharan Africans at one of the SHCS centres [4], it was found that the majority of those who had left the country had been denied asylum. An uncertain legal situation, with the risk of deportation through the asylum process, which has also been described in other countries, is likely to contribute to LTFU [28].

Older participants had a better retention rate, which is in accordance with other recent data [10,11,29]. Older age may be a proxy for less mobility and more comorbidity. Although a large proportion of participants with IDU as the transmission risk in Switzerland have stopped injecting drugs [30], IDU remains an important and independent risk factor for LTFU [10,11,29]. People with a higher baseline CD4 cell count or who were treatment-naïve were more prone to LTFU, a finding in congruence with research from France [29]. However, using time-updated CD4 cell counts for multivariable analyses, it was found that participants more likely to be lost to follow-up were those with lower latest CD4 cell counts. This has been observed in other cohort studies [10,29] in which time-updated CD4 cell counts were applied. Some of these patients may have been less adherent to treatment, or they may have died without documentation in the cohort database.

Immigrants were less likely to participate in the SHCS, with people from sub-Saharan Africa having the greatest probability of nonparticipation. Participating in the SHCS implies written informed consent. Concerns about disclosure could discourage sub-Saharan Africans from signing. Compared with other European countries with high numbers of immigrants, Switzerland has small, fractured immigrant groups that are divided by the barriers of the country's four different language regions. If immigrants rely on a small community of fellow nationals for support, they might be more inclined to avoid disclosure, fearing to risk their social status [31]. Among sub-Saharan Africans, men were the most vulnerable group for cohort nonparticipation. This is consistent with findings from African countries showing that men access ART less frequently and at a more advanced stage of HIV infection compared with women [32,33]. In qualitative research among sub-Saharan African migrant communities in the United Kingdom [34], all informants addressed the need to engage more with African men: for socio/cultural reasons they are greater risk-takers and more reluctant to admit a positive HIV status associated with stigma and dependence.

This study has certain limitations. While other research used only surrogate markers for region of origin, we classified regions of origin based on participants' nationality, which is most frequently used for international comparison at present [35]. However, use of nationality cannot discriminate between those who have immigrant status and those who have adopted Swiss nationality by marriage, which has important social implications. Another limitation is that it was not possible to make regular comprehensive linkages with the national death registry, for legal and technical reasons. With respect to cohort participation, undocumented immigrants do not even seek medical care in the existing network of HIV practitioners. Therefore, the participation bias is probably still underestimated. The strength of the SHCS is its national representativeness. Of note, a recent comparison with sales data from pharmaceutical companies revealed that 75% of the antiretroviral drugs sold in Switzerland from 2006 to 2008 were prescribed to participants in the SHCS [14]. Further, the nationwide network enabled us to assess cohort nonparticipation.

In conclusion, numbers of HIV-infected immigrants are increasing in the SHCS but immigrants are underrepresented in the SHCS, and are more likely to be lost to follow-up. Our data on nonparticipation, ART status and LTFU suggest that quality of care for immigrants may be less optimal, although healthcare insurance for all persons living in Switzerland is mandatory. Thus, qualitative research is needed to analyse underlying reasons for nonparticipation and LTFU of immigrants, also taking into account gender differences. To increase enrolment in the SHCS, enhance adherence to cohort visits and increase ART uptake and adherence to ART, for the benefit of vulnerable groups in Switzerland, and in Europe generally, we propose (i) to motivate immigrants to participate in the cohort and encourage them to remain in the cohort; (ii) to make use of mediators from sub-Saharan Africa with training in the support of people with HIV infection; (iii) to recruit male mediators who are able to follow up African men in a gender-sensitive way; (iv) to obtain information on the structural characteristics of local immigrant communities and enhance the empowerment of immigrants; and (v) to improve the training of Swiss healthcare providers in transcultural competency [36].

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Appendix

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References

1 International Organisation for Migration. *Global Estimates*. 2011. Available at www.iom.int/jahia/Jahia/about-migration/facts-and-figures/lang/en (accessed 5 May 2010).

2 Joint United Nations Programme on HIV/AIDS (UNAIDS). *Population Mobility and AIDS Technical update*, 2001. Available at http://data.unaids.org/publications/irc-pub02/jc513-popmob-tu_en.pdf (accessed 28 April 2010).

3 Swiss Federal Statistics Office (FSO). Ausländerinnen und Ausländer in der Schweiz, 2008. Available at www.bfs.admin.ch/bfs/portal/de/index/themen/01/22/publ.Document.114724.pdf (accessed 10 March 2010).

4 Swiss Federal Office of Public Health. HIV Epidemiology in Switzerland. Available at www.bag.admin.ch/hiv_aids/05464/05490/05749/05750/index.html?lang=en (accessed 10 June 2010).

5 Staehelin C, Egloff N, Rickenbach M, Kopp C, Furrer H. Migrants from sub-Saharan Africa in the Swiss HIV Cohort Study: a single center study of epidemiologic migration-specific and clinical features. *AIDS Patient Care STDS* 2004; **18**: 665–675.

6 Swiss Federal Office of Public Health. Migration and Public Health, Summary of the Federal Strategy Phase II (2008–2013). Vol 2011, 2008.

7 Staehelin C, Rickenbach M, Low N *et al*. Migrants from Sub-Saharan Africa in the Swiss HIV Cohort Study: access to antiretroviral therapy, disease progression and survival. *AIDS* 2003; **17**: 2237–2244.

8 Horstmann E, Brown J, Islam F, Buck J, Agins BD. Retaining HIV-infected patients in care: where are we? Where do we go from here? *Clin Infect Dis* 2010; **50**: 752–761.

9 Wolff H, Stalder H, Epiney M, Walder A, Irion O, Morabia A. Health care and illegality: a survey of undocumented pregnant immigrants in Geneva. *Soc Sci Med* 2005; **60**: 2149–2154.

10 Mocroft A, Kirk O, Aldins P *et al*. Loss to follow-up in an international, multicentre observational study. *HIV Med* 2008; **9**: 261–269.

11 Lanoy E, Mary-Krause M, Tattevin P *et al*. Predictors identified for losses to follow-up among HIV-seropositive patients. *J Clin Epidemiol* 2006; **59**: 829–835.

12 Poole WK, Perritt R, Shah KB *et al*. A characterisation of patient drop outs in a cohort of HIV positive homosexual/bisexual men and intravenous drug users. *J Epidemiol Commun Health* 2001; **55**: 66–67.

13 Sabin CA, Schwenk A, Johnson MA *et al*. Late diagnosis in the HAART era: proposed common definitions and associations with mortality. *AIDS* 2010; **24**: 723–727.

14 Schoni-Affolter F, Ledergerber B, Rickenbach M *et al*. Cohort profile: the Swiss HIV Cohort Study. *Int J Epidemiol* 2010: **39**: 1179–1189.

15 Joint United Nations Programme on HIV/AIDS. *AIDS epidemic update* UNAIDS 2007. Available at http://data.unaids.org/pub/epislides/2007/2007_epiupdate_en-pdf (accessed 1 January 2010).

16 Health Protection Agency. HIV in the United Kingdom: 2010 Report. Available at www.hpa.org.uk/web/HPAwebFile/HPAweb C/12591891830 (accessed 8 May 2010).

17 Caro-Murillo AM, Gutierrez F, Manuel Ramos J *et al*. HIV infection in immigrants in Spain: Epidemiological characteristics and clinical presentation in the CoRIS Cohort (2004–2006). *Enferm Infecc Microbiol Clin* 2009; **27**: 380–388.

18 Castilla J, Lorenzo JM, Izquierdo A *et al*. Characteristics and trends of newly diagnosed HIV-infections, 2000–2004. *Gac Sanit* 2006; **20**: 442–448.

19 Castilla J, Sobrino P, De La Fuente L, Noguer I, Guerra L, Parras F. Late diagnosis of HIV infection in the era of highly active antiretroviral therapy: consequences for AIDS incidence. *AIDS* 2002; **16**: 1945–1951.

20 Yebra G, Rivas P, Herrero MD *et al*. Clinical differences and viral diversity between newly HIV type 1-diagnosed African and non-African patients in Spain (2005–2007). *AIDS Res Hum Retroviruses* 2009; **25**: 37–44.

21 Althoff KN, Gange SJ, Klein MB *et al*. Late presentation for human immunodeficiency virus care in the United States and Canada. *Clin Infect Dis* 2010; **50**: 1512–1520.

22 Gagnon AJ, Merry L, Bocking J, Rosenberg E, Oxman-Martinez J. South Asian migrant women and HIV/STIs: knowledge, attitudes and practices and the role of sexual power. *Health Place* 2010; **16**: 10–15.

23 Corbett EL. HIV and tuberculosis: surveillance revisited. *Int J Tuberc Lung Dis* 2003; **8**: 1009–1021.
24 Rhodes T, Platt L, Maximova S *et al.* Prevalence of HIV, hepatitis C and syphilis among injecting drug users in Russia: a multi-city study. *Addiction* 2006; **101**: 252–266.
25 Kew MC. Epidemiology of chronic hepatitis B virus infection, hepatocellular carcinoma, and hepatitis B virus-induced hepatocellular carcinoma. *Pathol Biol (Paris)* 2010; **4**: 273–277.
26 Health Protection Agency. A Complex Picture. HIV & Other Sexually Transmitted Infections in the United Kingdom: 2006. Available at www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/0611ComplexPictureUKHIVSTI (accessed 15 February 2010).
27 Rosen S, Fox MP, Gill CJ. Patient retention in antiretroviral therapy programs in sub-Saharan Africa: a systematic review. *PLoS Med* 2007; **4**: e298.
28 Anderson J. Coming and going: some aspects of care for migrants with HIV in the UK. *J Infect* 2008; **57**: 11–15.
29 Ndiaye B, Ould-Kaci K, Salleron J *et al.* Incidence rate and risk factors for loss to follow-up in HIV-infected patients from five French clinical centres in Northern France – January 1997 to December 2006. *Antivir Ther* 2009; **14**: 567–575.
30 Weber R, Huber M, Rickenbach M *et al.* Uptake of and virological response to antiretroviral therapy among HIV-infected former and current injecting drug users and persons in an opiate substitution treatment programme: the Swiss HIV Cohort Study. *HIV Med* 2009; **10**: 407–416.
31 Fakoya I, Reynolds R, Caswell G, Shiripinda I. Barriers to HIV testing for migrant black Africans in Western Europe. *HIV Med* 2008; **9** (Suppl. 2): 23–25.
32 Braitstein P, Boulle A, Nash D *et al.* Gender and the use of antiretroviral treatment in resource-constrained settings: findings from a multicenter collaboration. *J Womens Health (Larchmt)* 2008; **17**: 47–55.
33 Muula AS, Ngulube TJ, Siziya S *et al.* Gender distribution of adult patients on highly active antiretroviral therapy (HAART) in Southern Africa: a systematic review. *BMC Public Health* 2007; **7**: 63.
34 Burns FM, Imrie JY, Nazroo J, Johnson AM, Fenton KA. Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilization of HIV health and social care services by African migrants in Britain. *AIDS Care* 2007; **19**: 102–108.
35 Del Amo J, Broring G, Hamers FF, Infuso A, Fenton K. Monitoring HIV/AIDS in Europe's migrant communities and ethnic minorities. *AIDS* 2004; **18**: 1867–1873.
36 Dominicé Dao MI, Ferreira JF, Vallier N, Roulin D, Hirschel B, Calmy A. Health perceptions of African HIV-infected patients and their physicians. *Patient Educ Couns* 2010; **80**: 185–190.