

Supplemental Appendix I. The rationale for the use of inverse probability of participation weights

The following table shows a simplified invented situation in the Swiss Childhood Cancer Survivor Study (SCCSS) with one dichotomous predictive factor (gender) for a possible prevalence estimate (smoking).

	Number of survivors in the total population of the SCCSS	Survivors who responded to the survey	Number of current smokers in those who responded	Percent of current smokers in those who responded	Probability to respond to the survey	Inverse of the probability to respond to the survey
Female	400	360	72	20%	90.0%	1.11
Male	600	300	150	50%	50.0%	2.00
Total	1000	660	222	34%		

We have 1000 eligible survivors of the SCCSS and 660 (66%) who responded to the survey with information on current smoking status. However, the response rate was not the same in males and females. A questionnaire was available for 90% of females and 50% of males. Among responders, 222 were current smokers (34%), 72 females (20%), and 150 males (50%). Clearly, it would be inappropriate to say that this observed prevalence of 34% of current smokers reflects the true prevalence of smoking among all 1000 survivors.

Obtaining a corrected prevalence estimate of smoking:

If we assume that for each gender the responders are representative of all the survivors of that gender, we can do the following calculation for the prevalence of smoking among all 1000 survivors. We expect to have 20% of smokers among all 400 women (80 expected to be current smokers) and 50% of smokers in all 600 men (300 expected to be current smoker). In total we expect 380 smokers among the 1000 survivors, i.e. a prevalence of 38%.

Mathematically, we get exactly the same result (38%) if we conducted a weighted analysis restricted to the 660 responders, using gender specific weights that are 1.11 and 2, derived as the inverse of the probability to have responded to the survey. This is what we called an analysis using *inverse probability of participation weights*. The advantages of the weighted approach are twofold. First, it can easily be extended to more than one predictive factor of a prevalence estimate using multivariable logistic regression. Second, in almost all statistical software it is possible to conduct an analysis in which the units of observation have differing statistical weight, and to obtain estimates and 95% confidence intervals that account for the weighting. However, we need to remember and acknowledge the assumption that all relevant predictive factors have been included in calculating the weights. The corrected prevalence estimate may still be biased, if this assumption does not hold. This is known as the assumption of no unmeasured confounding variables.

S1 Table. Questions and classification of typical outcomes of each section of the Swiss Childhood Cancer Survivor Study Questionnaire

	Name	Question	Answer categories	Classification
Somatic outcomes	Hypothyroidism	Underfunction of the thyroid gland	0 = No, currently not present 1 = Yes, currently present	0 = No hypothyroidism 1 = Hypothyroidism
	Visual impairments	Severe visual impairment or blind (on one or both eyes)	0 = No, currently not present 1 = Yes, currently present	0 = No visual impairments 1 = Visual impairments
	Hearing problems	Problems with hearing	0 = No, currently not present 1 = Yes, currently present	0 = No hearing problems 1 = Hearing problems
	Overweight	How tall are you? How much do you weight?		Body mass index $\leq 25\text{kg/m}^2$ = No overweight Body mass index $> 25\text{kg/m}^2$ = Overweight
	Any late effects	Do you suffer from late-effects of your former cancer disease?	0 = No 1 = Yes	0 = No late effects 1 = Any late effects
	Poor general health	How would you rate your general health status?	1 = Excellent 2 = Very good 3 = Good 4 = Not so good 5 = Poor	1-3 = Good general health 4-5 = Poor general health
Medical care	Regular follow-up	Do you still have regular follow-up care for your former cancer disease?	1 = Yes, I have regular follow-up care in my former cancer clinic 2 = Yes, I have regular follow-up care in another clinic or with another doctor 3 = No, my regular follow-up care is terminated but I sometimes visit a doctor 4 = No, my regular follow-up care is terminated and I haven't seen a doctor for a long time	3-4 = No regular follow-up 1-2 = Regular follow-up
	Frequent pain medication	Medication against pain and fever?	1 = Daily 2 = Several times per week 3 = Once a week 4 = Less than once a week	4 = No frequent pain medication 1-3 = Frequent pain medication
	Use alternative medicine	Do you use alternative medicine?	0 = No 1 = Yes	0 = No use of alternative medicine 1 = Use of alternative medicine

Mental outcomes	Concentration problems	Are you able to concentrate at school/at work?	1 = Excellent 2 = Very good 3 = Good 4 = Not so good 5 = Bad	1-3 = No concentration problems 4-5 = Concentration problems
	Psychological distress	Brief Symptom Inventory (BSI) 18		Transformed T-score <57 = No psychological distress Transformed T-score ≥57 = Psychological distress
Health behaviors	Engagement in sports activities	Do you engage in gymnastics, fitness, or sports?	0 = No 1 = Yes	0 = No engagement in sports activities 1 = Engagement in sports activities
	Current smoker	Have you ever smoked cigarettes?	0 = No, I never smoked cigarettes 1 = Yes, I smoked before but I am not smoking anymore 2 = Yes, I am currently smoking	0-1 = No current smoker 2 = Current smoker
	In partnership or marriage	Do you live in a partnership or marriage?	0 = No 1 = Yes	0 = No partnership or marriage 1 = In a partnership or marriage

S2 Table. Characteristics of survivors by type of response; risk ratios from multivariable multinomial logistic regression model

	Total (n=2328)		Early responders ^a (n=930)		Late responders ^b (n=671)		Non- responders ^c (n=727)		RR ^d early responders		RR ^d late responders		p-value ^d
	n	%	n	%	n	%	n	%	95% CI	95% CI			
<i>Gender</i>													<0.001
Male	1315	56.5	455	48.9	396	59.0	464	63.8	1		1		
Female	1013	43.5	475	51.1	275	41.0	263	36.2	1.94	1.57-2.41	1.29	1.02-1.62	
<i>Age (years)</i>													0.008
< 20	468	20.1	179	19.3	116	17.3	173	23.8	1		1		
20 - 29	1144	49.1	424	45.6	365	54.4	355	48.8	1.14	0.85-1.53	1.54	1.12-2.11	
30 - 39	564	24.2	258	27.7	151	22.5	155	21.3	1.81	1.17-2.80	1.68	1.05-2.69	
≥ 40	152	6.5	69	7.4	39	5.8	44	6.1	1.71	0.86-3.40	1.52	0.72-3.18	
<i>Language region of Switzerland</i>													0.053
German	1684	72.3	710	76.4	469	69.9	505	69.5	1		1		
French	561	24.1	189	20.3	178	26.5	194	26.7	0.72	0.56-0.92	0.99	0.77-1.28	
Italian	83	3.6	31	3.3	24	3.6	28	3.9	0.83	0.48-1.46	0.92	0.51-1.65	
<i>Nationality</i>													<0.001
Swiss	2017	89.3	868	93.4	602	89.7	547	83.0	1		1		
German, Austrian, French, Italian ^e	102	4.5	35	3.8	28	4.2	39	5.9	0.53	0.33-0.86	0.64	0.39-1.07	
Other	140	6.2	26	2.8	41	6.1	73	11.1	0.26	0.16-0.42	0.55	0.36-0.84	
<i>Neighborhood index of SEP</i>													
First tertile (lowest SEP)	678	33.4	258	32.2	207	35.0	213	33.2	n.a. ^f				
Second tertile	678	33.4	278	34.7	186	31.5	214	33.4					
Third tertile (highest SEP)	677	33.3	265	33.1	198	33.5	214	33.4					
<i>Diagnosis (ICCC-3)</i>													0.599
I Leukemia	784	33.7	343	36.9	231	34.4	210	28.9	1		1		
II Lymphoma	441	18.9	154	16.6	137	20.4	150	20.6	0.66	0.48-0.91	0.83	0.60-1.16	
III CNS tumor	326	14.0	128	13.8	83	12.4	115	15.8	0.81	0.55-1.21	0.86	0.56-1.31	
IV Neuroblastoma	102	4.4	41	4.4	27	4.0	34	4.7	0.85	0.50-1.47	0.81	0.45-1.47	
V Retinoblastoma	57	2.5	19	2.0	18	2.7	20	2.8	0.66	0.32-1.36	0.98	0.47-2.03	
VI & VII Renal & hepatic tumor	152	6.5	69	7.4	49	7.3	34	4.7	1.27	0.78-2.06	1.32	0.79-2.19	
VIII Bone tumor	108	4.6	45	4.8	33	4.9	30	4.1	1.02	0.59-1.75	1.07	0.60-1.88	
IX Soft tissue sarcoma	132	5.7	52	5.6	37	5.5	43	5.9	0.77	0.47-1.25	0.80	0.48-1.34	
X Germ cell tumor	75	3.2	28	3.0	17	2.5	30	4.1	0.53	0.29-0.95	0.55	0.28-1.05	
XI & XII Other tumor	41	1.7	10	1.1	11	1.6	20	2.8	0.50	0.20-1.20	0.80	0.34-1.90	
Langerhans cell histiocytosis	110	4.7	41	4.4	28	4.2	41	5.6	0.69	0.40-1.19	0.76	0.42-1.36	

<i>Treatment</i>											0.527	
Surgery only	289	12.6	110	11.9	66	9.9	113	16.2	0.86	0.58-1.29	0.64	0.41-1.00
Chemotherapy ^g	1126	49.2	461	49.8	340	51.1	325	46.5	1		1	
Radiotherapy ^h	778	34.0	312	33.8	232	34.9	234	33.5	0.94	0.72-1.22	0.97	0.74-1.28
Bone marrow transplantation	95	4.2	41	4.4	27	4.1	27	3.9	1.13	0.66-1.96	1.00	0.56-1.79
<i>Relapse</i>												
No	2033	87.3	819	88.1	587	87.5	627	86.2	n.a. ^f			
Yes	295	12.7	111	11.9	84	12.5	100	13.8				
<i>Age at diagnosis (years)</i>												
< 5	841	36.1	364	37.2	234	34.9	261	35.9	n.a. ^f			
5 - 9.9	635	27.3	241	25.9	195	29.0	199	27.4				
≥ 10	852	36.6	343	36.9	242	36.1	267	36.7				
<i>Time since diagnosis (years)</i>											0.432	
< 10	240	10.3	84	9.0	58	8.6	98	13.5	1		1	
10 - 19.9	1025	44.0	380	40.9	308	45.9	337	46.4	0.75	0.53-1.07	0.66	0.45-0.97
20 - 29.9	817	35.1	352	37.9	242	36.1	223	30.7	1.12	0.83-1.51	1.01	0.74-1.38
≥ 30	246	10.6	114	12.3	63	9.4	69	9.5	1.18	0.68-2.04	1.03	0.57-1.85

^a Survivors who responded to the initial questionnaire sent (40.0%).

^b Survivors who responded only after reminding them (28.8%).

^c Survivors who did not respond at all (31.2%).

^d RRs and p-values from a multivariable multinomial regression model comparing early and late responders with non-responders.

^e Questionnaires were available in their mother languages (German, French, Italian).

^f Factors not associated in the univariable regression models were excluded from the multivariable model.

^g Chemotherapy may include surgery.

^h Radiotherapy may include chemotherapy or surgery.

Abbreviations: CI, Confidence Interval; CNS, Central Nervous System; ICC3-3, International Classification of Childhood Cancer – third edition; n.a., not applicable; n, number; RR, Risk Ratio; SEP, Socio-Economic Position.