## Articles

# Complete cancer prevalence in Europe in 2020 by disease duration and country (EUROCARE-6): a population-based study

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## **Summary**

**Background** Cancer survivors—people living with and beyond cancer—are a growing population with different health needs depending on prognosis and time since diagnosis. Despite being increasingly necessary, complete information on cancer prevalence is not systematically available in all European countries. We aimed to fill this gap by analysing population-based cancer registry data from the EUROCARE-6 study.

Methods In this population-based study, using incidence and follow-up data up to Jan 1, 2013, from 61 cancer registries, complete and limited-duration prevalence by cancer type, sex, and age were estimated for 29 European countries and the 27 countries in the EU (EU27; represented by 22 member states that contributed registry data) using the completeness index method. We focused on 32 malignant cancers defined according to the third edition of the International Classification of Diseases for Oncology, and only the first primary tumour was considered when estimating the prevalence. Prevalence measures are expressed in terms of absolute number of prevalent cases, crude prevalence proportion (reported as percentage or cases per 100 000 resident people), and age-standardised prevalence proportions up to Jan 1, 2020, using linear regression.

**Findings** In 2020, 23711 thousand (95% CI 23565–23857) people ( $5 \cdot 0\%$  of the population) were estimated to be alive after a cancer diagnosis in Europe, and 22347 thousand (95% CI 22210–22483) in EU27. Cancer survivors were more frequently female (12818 thousand [95% CI 12720–12917]) than male (10892 thousand [10785–11000]). The five leading tumours in female survivors were breast cancer, colorectal cancer, corpus uterine cancer, skin melanoma, and thyroid cancer (crude prevalence proportion from 2270 [95%CI 2248–2292] per 100 000 to 301 [297–305] per 100 000). Prostate cancer, colorectal cancer, urinary bladder cancer, skin melanoma, and kidney cancer were the most common tumours in male survivors (from 1714 [95% CI 1686–1741] per 100 000 to 255 [249–260] per 100 000). The differences in prevalence between countries were large (from 2 to 10 times depending on cancer type), in line with the demographic structure, incidence, and survival patterns. Between 2010 and 2020, the number of prevalent cases increased by  $3 \cdot 5\%$  per year (41% overall), partly due to an ageing population. In 2020, 14850 thousand (95% CI 14681–15018) people were estimated to be alive more than 5 years after diagnosis and 9099 thousand (8909–9288) people were estimated to be alive more than 10 years after diagnosis, representing an increasing proportion of the cancer survivor population.

Interpretation Our findings are useful at the country level in Europe to support evidence-based policies to improve the quality of life, care, and rehabilitation of patients with cancer throughout the disease pathway. Future work includes estimating time to cure by stage at diagnosis in prevalent cases.

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#### Introduction

Cancer survivors (ie, any individual diagnosed with cancer who is living) are a relatively understudied population with diverse care needs depending on prognostic factors and the phase of care (first line, surveillance, or terminal care). Representative and reliable indicators quantifying cancer prevalence by disease duration over time are essential to develop follow-up guidelines, prevent late health effects, better tackle the causes of inequalities, and improve patients' quality of life. The rapid increase in the number of cancer survivors in all ageing societies, combined with the cost of innovative therapies, poses a major challenge to the sustainability of public health systems. Detailed and comparable prevalence indicators are therefore also increasingly needed for cancer control planning and Health Technology Assessment.

Cancer prevalence in a population indicates the number (or proportion) of people living after a cancer diagnosis at a given time (ie, the index date). This



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See Online for appendix

### Research in context

#### Evidence before this study

We searched MEDLINE on April 18 and May 9, 2023, focusing on documents published in English since Jan 1, 2002, when the EUROPREVAL project published the first complete cancer prevalence estimation in Europe using population-based cancer registry data. We combined search terms relevant to cancer ("cancer", "neoplasms") and to registries ("population-based", "registries"), with terms restricting the focus to prevalence ("prevalence", "survivors") and the European area ("Europe"). We excluded irrelevant reports (prevalence of cancer as comorbid condition and prevalence of risk factors and other conditions). We prioritised evidence from population-based studies. We identified a growing body of evidence on the health-care needs of cancer survivors in Europe, but information on their actual number and characterisation is scattered and not comprehensive. Systematic estimates of cancer prevalence by country are provided by the International Agency for Research on Cancer only for short-term follow-up (within 5 years from diagnosis). By contrast, complete prevalence, including all people living longer than 5 years after a cancer diagnosis, is not routinely available in Europe. A main reason for this is that, unlike incidence or survival, complete prevalence cannot be measured from cancer registry data, but it must be estimated using specific methods to compensate for limited follow-up.

#### Added value of this study

This study quantifies and characterises the total cancer prevalence by country in Europe in 2020 using, to our knowledge, the largest available population-based dataset (EUROCARE-6). The number and proportion of cancer survivors are estimated for 32 cancer entities by sex, age, disease duration, and time period in 29 European countries, including the UK and European Free Trade Association countries. The size of the population covered (61 cancer registries, 23 of which are national) strengthens the representativeness of the study. A unique data collection protocol and central quality control maximised the standardisation of individual data. The completeness index method was used to optimise the accuracy and international comparability of the estimates. The study identifies the most common cancers among prevalent cases. The demographic and case-mix characteristics of cancer survivors differ from those of incident and deceased cancer cases. The differences between countries are also remarkably greater than for cancer incidence or mortality. Cancer survivors beyond 5 years are found to be a dominant and increasing proportion of the cancer survivor population. Prevalence time trends differ by cancer with a varying effect of demographic ageing.

#### Implications of all the available evidence

Long-term cancer survivorship implies emerging health and social needs that require an integrated approach throughout the life course. Oncological rehabilitation should address all the needs of survivors, including psychological, cognitive, social, sexual, and nutritional symptoms. Our results allow identification of specific high-risk populations and are helpful in defining priorities for intervention and in the Health Technology Assessment domain. Our results can usefully complement studies on cancer recovery (time to cure) and quality of life conducted in representative patient cohorts. Prevalence estimates at the threshold of the COVID-19 era provide a baseline with which to compare the evidence that will emerge from population data after 2020, which is currently limited in Europe. There is an increasing need for comprehensive cancer prevalence estimates with continuity, detail, and systematicity in Europe. The joint analysis of data from European cancer registries provides immense added value to what individual countries can do and should be sustained over time.

For the **Global Cancer Observatory** see https://gco.iarc.fr/ estimate includes all people who have ever been diagnosed, regardless of the time since diagnosis or whether they are still under treatment or cured. Cancer prevalence can be measured from incidence and survival data collected by population-based cancer registries by counting incident cases alive at the index date. However, observed prevalence, unlike other registry statistics, is intrinsically incomplete because it cannot include living people diagnosed before the start of registration. A virtually complete observed prevalence is only released by registries operating for five or more decades. Commonly, registration periods are shorter than five decades and the number of cancer survivors, at any time after diagnosis, can only be estimated using statistical models.

Worldwide comparable estimates of cancer prevalence limited to 5 years after diagnosis and based on projections of cancer incidence and mortality are provided by the International Agency for Research on Cancer (IARC; see the Global Cancer Observatory) for all European countries.<sup>1</sup> Conversely, despite its informative potential, complete cancer prevalence is not systematically estimated in all European countries with active population-based registries.

To fill this information gap, the European Innovative Partnership for Action Against Cancer (iPAAC) Joint Action has promoted the estimation and dissemination of complete cancer prevalence indicators at the country level in Europe.<sup>2</sup>

We report the main results of this joint effort to estimate complete cancer prevalence in 2020 by country in Europe. Particular attention has been paid to analyse the proportion of long-term survivors. We also assessed how much of the increase in prevalence between 2010 and 2020 can be explained by demographic ageing or changes in incidence and survival.

## **Methods**

## Study design and data collection

This population-based study was based on the EUROCARE-6 study dataset.3 This dataset includes standardised information on patients' diagnosis and life status, and on life expectancy in the general population, which was collected from European cancer registries using a unique study protocol.4 The data were quality assured according to the European Network of Cancer Registries, Joint Research Centre,5 and EUROCARE6 criteria. The validity of individual records was checked to identify errors and anomalies in single variables (semantic checks) or between multiple variables (internal consistency). Missing or invalid values in compulsory variables were classified as major errors and excluded from the analyses.

The final EUROCARE-6 database contains information on more than 26 million patients diagnosed with cancer between 1978 and 2015 and followed up until Dec 31, 2016, at the latest. Overall, 109 cancer registries from 29 countries contributed data. Population coverage is national in 23 countries and partial in six countries (France, Germany, Italy, Portugal, Spain, and Switzerland). As a result, the EUROCARE-6 dataset covers 64% of the population of the 29 participating countries (478 million inhabitants; the European pool) and 52% of the population of 27 countries in the EU (EU27) represented by 22 member states (Greece, Hungary, Luxembourg, Romania, and Sweden did not contribute).

For prevalence estimation, we selected 61 general cancer registries with prevalence data available up to Jan 1, 2013-the most recent common index date for most cancer registries-and registries that had been active since at least 2003 (2004 only for the national registries of Belgium and Cyprus). The index date was Jan 1, 2013, for all registries except those of Slovakia (Jan 1, 2011) and the Canary Islands (Spain), Croatia, Ferrara (Italy), Saarland (Germany), Sassari (Italy), Tarragona (Spain), and Varese (Italy; Jan 1, 2012). These exceptions allowed greater population coverage in Europe and in Germany, Italy, and Spain, where many registries did not meet the selection requirements. Countries were grouped into five macro areas: central, eastern, northern, and southern Europe, and Ireland and the UK (appendix pp 12-14).

We focused on a list of 32 malignant cancers defined according to the third edition of the International Classification of Diseases for Oncology. Given the heterogeneous classification of behaviour between countries, brain and urinary bladder cancer are defined to also include benign, uncertain, and in situ cancers to improve comparability (appendix p 15). For each cancer site (specific site or all cancers combined), only the first primary tumour was considered (person-based prevalence). People with multiple primary cancers contribute to the prevalence counts of each specific cancer type. Therefore, cancer-specific prevalence counts do not sum to the counts for all cancers combined.

## Statistical analysis

Prevalence measures are expressed in terms of absolute number of prevalent cases, crude prevalence proportion (reported as percentage or cases per 100000 resident people), and age-standardised prevalence proportion based on the European Standard Population 2013.7

Registry-specific observed limited-duration prevalence was calculated by cancer, sex, and 5-year age group (attained age at the prevalence index date) with the counting method using SEER\*Stat software For SEER\*Stat software see (version 8.3.5). Observed limited-duration prevalence corresponds to the number of survivors diagnosed within the previous 1, 2, 3, ... L years from the index date, where L is the maximum length of registration period. Individuals lost to follow-up who were estimated to be alive are counted using registry-specific life-tables stratified by cancer, sex, age group, and 10-year period of diagnosis (appendix p 5).

Registry-specific complete prevalence was estimated from observed prevalence data with the completeness index method<sup>8,9</sup> using COMPREV software (version 3.0.9). This method involves adjusting the registry-specific observed prevalence by a correction factor, known as the completeness index, which quantifies the theoretical completeness of observed prevalence as a function of the registration time length (appendix p 5). This adjustment enables supplementation of the prevalence observable at the maximum duration with the unobservable part-ie, accounting for individuals diagnosed before the start of registration.

European completeness indexes (or R-indexes) were estimated by modelling cancer-specific trends of incidence and relative survival observed by the registries with at least 30 years of observation (appendix pp 6-8, 26, 27).<sup>3</sup> Country-specific complete prevalence estimates for countries with local registration systems were obtained by pooling registry-specific estimates and applying age-specific pooled estimates to the national resident population stratified by age group (0-54, 55-64, 65–74, and ≥75 years). Country-specific complete prevalence estimates were derived for the latest index date and in the previous 5 years to extrapolate projections on the basis of the latest prevalence observations. Country-specific prevalence estimates were projected to Jan 1, 2020, with linear regression by extrapolating the prevalence time trend over the last three available index dates. A sensitivity analysis was conducted using linear and logistic regression and alternative basis for projections (prevalence in the last three, four, or five index dates). For each sensitivity scenario, the regression was applied to prevalence estimates smoothed with 3-year moving averages and stratified by sex and age (0-54, 55-64, 65-74, and ≥75 years). Validation against published observed prevalence data for 2014-16 in Nordic

https://seer.cancer.gov/seerstat/

For COMPREV software see https://surveillance.cancer.gov/ comprev/

## Articles

	Population	Population (thousands)			Number of prevalent cases (thousands)	lent cases (th	ousands)			Crude preval	Crude prevalence per 100 000	000	Age-standardised prevalence per 100 000	dised prevale	ence
	Total population	Proportion of European pool	Females	Males	Total population	Proportion of European pool	Females	Males	Female- to-male ratio	Total population	Females	Males	Total population	Females	Males
Northern Europe	17 080	3.6%	8561	8519	868 (860–875)	3·7%	473 (466-479)	395 (390-400)	1.2	5080 (5034- 5126)	5520 (5447– 5594)	4637 (4582- 4693)	5065 (5020- 5110)	5204 (5133- 5274)	5015 (4960– 5070)
Denmark	5823	1.2%	2926	2897	312 (306–318)	1.3%	175 (169–180)	137 (134-140)	1.3	5354 (5250- 5459)	5975 (5791- 6159)	4727 (4628– 4826)	5312 (5209- 5415)	5669 (5491- 5847)	4985 (4886– 5084)
Finland	5525	1.2%	2797	2728	277 (272–281)	1.2%	155 (153-158)	121 (118-125)	1.3	5004 (4928– 5081)	5548 (5458- 5638)	4447 (4324- 4570)	4598 (4529- 4668)	4779 (4701- 4857)	4540 (4425- 4655)
Iceland	364	0.1%	177	187	15 (15-16)	0.1%	8 (6-8)	7 (6-7)	1.1	4164 (3996– 4333)	4760 (4440- 5079)	3 600 (3 475- 3 725)	5 108 (4 903- 5 313)	5463 (5 086– 5 840)	4 840 (4 698- 4 981)
Norway	5368	1.1%	2661	2707	264 (262–267)	1.1%	134 (132-136)	130 (128-132)	1.0	4922 (4874- 4970)	5041 (4968- 5115)	4804 (4743- 4866)	5348 (5297– 5399)	5176 (5100- 5251)	5640 (5574- 5707)
Central Europe	196 924	41.2%	100377	96547	11029 (10911-11148)	46.5%	5842 (5765-5918)	5188 (5097–5279)	1.1	5601 (5541- 5661)	5820 (5743- 5896)	5374 (5280– 5467)	5288 (5230- 5346)	5216 (5143- 5290)	5514 (5423- 5605)
Austria	8901	1.9%	4522	4379	408 (402-414)	1.7%	214 (211-217)	194 (189–199)	1.1	4583 (4521– 4646)	4732 (4671- 4793)	4429 (4319- 4540)	4531 (4466- 4596)	4397 (4335- 4459)	4810 (4689- 4931)
Belgium	11522	2.4%	5841	5681	657 (650–664)	2.8%	368 (365-372)	289 (283–294)	1.3	5701 (5641- 5761)	6305 (6242- 6369)	5080 (4977– 5183)	5705 (5644- 5766)	5954 (5896– 6013)	5574 (5466- 5682)
France	67320	14.1%	34788	32 533	3772 (3716–3828)	15.9%	1998 (1974–2022)	1774 (1723-1825)	1.1	5603 (5519- 5686)	5744 (5676- 5812)	5452 (5296– 5609)	5439 (5358– 5519)	5266 (5204- 5327)	5822 (5657- 5987)
Germany	83167	17.4%	42129	41038	4874 (4771–4978)	20.6%	2538 (2466–2611)	2336 (2262–2410)	1.1	5861 (5736- 5986)	6025 (5853- 6197)	5692 (5512- 5873)	5290 (5171- 5409)	5180 (5013- 5348)	5554 (5387- 5720)
Netherlands	17 408	3.6%	8760	8648	875 (865-884)	3.7%	489 (483-494)	386 (378-394)	1:3	5026 (4970- 5081)	5581 (5519- 5642)	4463 (4372- 4555)	5006 (4951– 5061)	5321 (5261- 5382)	4757 (4660- 4855)
Switzerland	8606	1.8%	4337	4269	444 (437–450)	1.9%	234 (229-239)	210 (205–214)	1:1	5154 (5077- 5231)	5395 (5287– 5503)	4910 (4801- 5018)	5223 (5147– 5300)	5156 (5061– 5251)	5402 (5281- 5 522)
Eastern Europe	67 092	14.0%	34597	32 495	2332 (2315-2349)	9.8%	1371 (1358-1385)	961 (951-971)	1.4	3476 (3451- 3502)	3963 (3924- 4002)	2958 (2927– 2990)	3538 (3513- 3562)	3656 (3620- 3691)	3560 (3526- 3593)
Bulgaria	6951	1.5%	3582	3370	215 (212–219)	%6.0	135 (132-139)	80 (78-82)	1.7	3099 (3043- 3154)	3783 (3685- 3880)	2372 (2321- 2422)	2905 (2850- 2960)	3295 (3209- 3381)	2526 (2470- 2583)
Czechia	10694	2.2%	5422	5272	498 (495-500)	2.1%	270 (268–272)	228 (227–229)	1.2	4656 (4632- 4680)	4977 (4934- 5020)	4326 (4306- 4347)	4683 (4659- 4707)	4584 (4541- 4627)	4957 (4933- 4981)
Estonia	1329	0·3%	700	629	56 (55-57)	0.2%	31 (30–32)	25 (24-26)	1.2	4214 (4129- 4300)	4433 (4299- 4566)	3971 (3868- 4075)	4109 (4027- 4192)	3823 (3724- 3922)	4912 (4788- 5035)
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	rupulation	гориацоп (споизапαs)			Number of prevalent cases (thousands)	alent cases ( un	ousands)			Crude prevalence per 100 000	lence per 100	000	Age-standar per 100 000	Age-standardised prevalence per 100 000	ence
	Total population	Proportion of European pool	Females	Males	Total population	Proportion of European pool	Females	Males	Female- to-male ratio	Total population	Females	Males	Total population	Females	Males
(Continued from previous page)	n previous pa	ge)													
Latvia	1908	0.4%	1027	881	78 (97–77)	%E·0	48 (47-49)	30 (30-31)	1.6	4097 (4033- 4160)	4652 (4554- 4750)	3449 (3374- 3524)	3884 (3826- 3942)	3925 (3853- 3996)	4145 (4065- 4225)
Lithuania	2794	0.6%	1490	1304	130 (128–133)	0.5%	72 (70-73)	58 (56-61)	1.2	4659 (4567- 4751)	4821 (4729- 4913)	4475 (4309- 4641)	4462 (4377- 4547)	4176 (4094- 4258)	5342 (5175- 5509)
Poland	37 958	%6.7	19 585	18373	1149 (1133-1164)	4.8%	698 (685-710)	451 (441-460)	1.5	3026 (2985- 3067)	3562 (3499- 3626)	2454 (2403- 2506)	3138 (3098- 3177)	3341 (3283- 3398)	3032 (2978– 3087)
Slovakia	5458	1.1%	2793	2665	206 (203-210)	%6·0	117 (115-120)	89 (86-91)	1:3	3775 (3710- 3840)	4208 (4117- 4298)	3322 (3229- 3414)	4183 (4111- 4256)	4178 (4086- 4270)	4411 (4300- 4521)
Southern Europe	124827	26.1%	63 994	60 832	6489 (6424-6554)	27.4%	3472 (3419–3524)	3017 (2979–3056)	1.2	5198 (5146– 5250)	5425 (5343- 5507)	4960 (4897– 5023)	4795 (4746– 4843)	4778 (4706– 4851)	4955 (4892- 5017)
Croatia	4058	0.8%	2087	1972	186 (182-191)	0.8%	105 (102–109)	81 (79-83)	1.3	4593 (4482- 4704)	5050 (4865- 5236)	4108 (3992- 4225)	4298 (4193- 4403)	4365 (4223- 4508)	4369 (4236- 4502)
Cyprus	888	0.2%	454	434	36 (35–37)	0.2%	20 (19–20)	16 (16-17)	1:3	4067 (3981- 4154)	4386 (4258- 4514)	3735 (3619- 3850)	4608 (4511- 4705)	4733 (4593- 4872)	4559 (4424- 4695)
Italy	59 641	12.5%	30591	29 050	3514 (3453-3574)	14.8%	1939 (1890–1988)	1575 (1540–1610)	1.2	5891 (5790– 5993)	6338 (6177– 6498)	5421 (5301- 5542)	5184 (5095- 5273)	5375 (5239- 5511)	5102 (4990- 5214)
Malta	515	0.1%	249	266	19 (19–20)	0.1%	11 (11-12)	8 (8-8)	1.4	3789 (3639- 3938)	4564 (4287- 4841)	3063 (2934- 3192)	3998 (3849- 4147)	4458 (4191- 4724)	3613 (3475- 3750)
Portugal	10 296	2.2%	5436	4860	477 (472–483)	2.0%	265 (261–268)	212 (208-216)	1:3	4635 (4582- 4687)	4870 (4803- 4937)	4371 (4289- 4454)	4229 (4182- 4277)	4262 (4198- 4325)	4321 (4236– 4405)
Slovenia	2096	0.4%	1045	1051	99 (98-100)	0.4%	52 (51–53)	47 (46-48)	1.1	4711 (4654- 4768)	4936 (4844- 5028)	4487 (4419- 4555)	4518 (4464- 4572)	4403 (4322- 4484)	4802 (4734- 4869)
Spain	47333	%6.6	24 133	23199	2157 (2135-2180)	9.1%	1080 (1063-1097)	1078 (1062–1093)	1.0	4558 (4510- 4606)	4475 (4404- 4546)	4645 (4579- 4710)	4471 (4421- 4520)	4153 (4083- 4224)	4988 (4915- 5060)
Ireland and the UK	71 990	15.1%	36444	35546	2992 (2940–3044)	12.6%	1662 (1632-1692)	1331 (1288–1373)	1.2	4156 (4084- 4228)	4559 (4477- 4642)	3743 (3625- 3862)	4377 (4301- 4453)	4578 (4493- 4663)	4218 (4080- 4356)
England	56481	11.8%	28560	27921	2296 (2245-2348)	9·7%	1280 (1250-1310)	1017 (975-1059)	1:3	4066 (3974- 4157)	4481 (4376- 4585)	3641 (3491- 3791)	4262 (4166- 4358)	4480 (4372- 4587)	4085 (3911– 4258)
Ireland	4964	1.0%	2507	2458	215 (213-217)	%6.0	109 (108-110)	106 (104-108)	1.0	4333 (4289- 4376)	4343 (4294- 4392)	4322 (4250- 4394)	5343 (5285- 5400)	5090 (5025- 5154)	5090 5676 (5025- (5581- 5154) 5770)

	Population	Population (thousands)			Number of prevalent cases (thousands)	alent cases (th	iousands)			Crude prevalence per 100 000	ence per 100	000	Age-standardised prevalence per 100 000	dised prevale	исе
	Total population	Total Proportion Females Males population of European pool	Females	Males	Total population	Proportion of European pool	Females	Males	Female- to-male ratio	Total population	Females	Males	Total population	Females	Males
(Continued from previous page)	n previous pa	ge)													
Northern Ireland	1901	0.4%	965	936	80 (79-82)	0.3%	45 (44-46)	35 (34-37)	1.3	4232 (4142- 4323)	4687 (4598- 4776)	3764 (3605- 3923)	4721 (4614- 4827)	4947 (4852- 5042)	4550 (4326- 4773)
Scotland	5481	1.1%	2810	2671	250 (247–254)	1.1%	145 (143-147)	105 (103–108)	1.4	4562 (4498- 4625)	5157 (5074- 5240)	3936 (3840- 4032)	4607 (4544- 4670)	4957 (4877- 5038)	4276 (4178- 4374)
Wales	3163	%2.0	1603	1559	150 (148–153)	%9·0	83 (81–85)	(69-99)	1.2	4756 (4681- 4830)	5178 (5077- 5279)	4322 (4212- 4432)	4546 (4475- 4616)	4752 (4660- 4844)	4380 (4266– 4495)
European pool 477 913	477 913	100%	243974 233939	233 939	23 711 (23 565-23 857)	100%	12818 (12720- 12917)	10 892 (10785- 11 000)	1.2	4961 (4931- 4992)	5254 (5213- 5295)	4656 (4610- 4702)	4783 (4754- 4813)	4785 (4747- 4823)	4918 (4872- 4965)
EU27*	447320	:	228764 218556	218 556	22 347 (22 210-22 483)	:	12 <i>077</i> (11982- 12171)	10270 (10171- 10369)	1.2	4996 (4965- 5026)	5279 (5238- 5320)	4699 (4654- 4744)	4767 (4737- 4796)	4747 (4708- 4784)	4941 (4896- 4986)
Number of prevals (Greece, Hungary,	ent cases (thou Luxembourg, l	sands), crude al Romania, and S	nd age-stanc weden did no	łardised (Eur ot contribute	Number of prevalent cases (thousands), crude and age-standardised (European Standard Population 2013) prevalence proportions per 100 000 inhabitants with 95% CIs in parentheses. *27 countries in the EU represented by 22 member states (Greece, Hungary, Luxembourg, Romania, and Sweden did not contribute so values for these countries were estimated from the corresponding macro region prevalence).	ulation 2013) p countries were 6	rrevalence propc	ortions per 100 000 the corresponding	0 inhabitants 3 macro regio	s with 95% Cls in in prevalence).	parentheses. *	27 countries in t	he EU representec	d by 22 membe	er states

registries<sup>10</sup> allowed us to choose the linear model with 3-year basis for projections (data not shown). Complete (and limited-duration) prevalence was then projected annually from Jan 1, 2014, to Jan 1, 2020, through the final estimated model parameters. Projected versus observed prevalence estimates in the Nordic registries 2014–20<sup>10</sup> are shown in the appendix (pp 28–29).

Estimates at the European level are provided for the 29 participating countries (European pool) and for EU27, assuming prevalence equal to the respective macro area for the five EU27 countries not participating in EUROCARE-6.

Complete prevalence difference between Jan 1, 2010, and Jan 1, 2020, was decomposed by determinant to quantify the effect of incidence and survival changes compared with demographic changes. The prevalence change due to ageing is the difference in population between Jan 1, 2020, and Jan 1, 2010, applied to prevalence estimates in 2010. The prevalence change due to incidence and survival dynamics is the difference in prevalence between Jan 1, 2020, and Jan 1, 2010, applied to population in 2020.

The delta method was used to compute the SE of prevalence estimates up to 2013 (from the known variance of the observed prevalence and completeness indices) and the SE of prevalence projections (from the variance of the linear slope parameter). For all indicators, 95% CIs were estimated from SEs assuming a normal distribution. Further methodological details are provided in the appendix (pp 4–10). Statistical analyses were performed with SAS (version 9.4).

### Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

## Results

Table 1: Population (thousands) and estimated complete cancer prevalence in Europe (European pool of 29 countries in EUROCARE-6 and EU27) by country and sex as of Jan 1, 2020

A total of 19538317 primary cancer cases across the 61 cancer registries were confirmed to be eligible and included in the analysis. The duration of observation at the index date ranged from 9 years to 35 years (median length 20 years [IQR 16–28]). The proportion of records excluded due to major errors was 0.9% overall and never exceeded 3% for any one registry. Proportion of cases censored alive before the index date (ie, lost to follow-up) was 0.6% overall (37575 of 6412099 individuals alive at the index date) and was below 3.0% for most registries (appendix p 3). Recording of non-malignant cases of urinary bladder and brain cancer was not consistent across Europe and was missing in some registries or countries (appendix pp 12–14).

Overall, in the 29 European countries covered by the study (477913 thousand inhabitants), 23711 thousand (95% CI 23565–23857) people with a previous cancer diagnosis were estimated to be alive on Jan 1, 2020, irrespective of when they were diagnosed. They represent

ancer 2 2 2	Age 55-64 years 7773 4960 (7630-7915) 3638 31 (3575-3702) 586 (559-613)	Age 65–74 years	A co	1							
er ancer ine cancer	(96		⊳rye ≥75 years	All ages	Age 0-54 years	Age 55-64 years	Age 65-74 years	Age ≥75 years	All ayes	Age 0–54 years	Age ≥75 years
er ancer ine cancer	(96										
		12 892 ) (12 604-13 179)	16 144 (16 033-16 254)	5254 (5213–5295)	2316 (2291-2341)	2548 (2501–2594)	3482 (3404-3559)	4473 (4442-4504)	12 818 (12 720-12 917)	18%	35%
	586 (559–613)	6163 (5996–6329)	6518 (6466–6570)	2270 (2248–2292)	876 (863-889)	1193 (1172-1213)	1664 (1619–1709)	1806 (1791–1820)	5539 (5486–5592)	16%	33%
		1290 (1238–1342)	2685 (2652-2717)	564 (557–572)	92 (91-94)	192 (183-201)	348 (334-362)	744 (735-753)	1377 (1358–1396)	7%	54%
	481 (454–508)	1067 (1039-1094)	1563 (1533-1593)	382 (376–388)	54 (52-55)	158 (149–167)	288 (281–295)	433 (425-441)	932 (918–947)	6%	46%
Skin melanoma (146–149) (144–149)	443 9) (430-456)	692 (669–715)	786 (774-799)	319 (315-323)	229 (225-233)	145 (141-149)	187 (181–193)	218 (214-221)	779 (770–788)	29%	28%
Thyroid cancer 167 (164-170)	520 0) (499-541)	660 (642–678)	447 (430-464)	301 (297–305)	261 (257–266)	170 (164-177)	178 (173-183)	124 (119–128)	734 (724-744)	36%	17%
Cervical uterine cancer 102 (100–104)	465 4) (439-491)	484 (458-510)	657 (620-695)	256 (250–263)	160 (157-163)	152 (144-161)	131 (124-138)	182 (172-192)	625 (610-641)	26%	29%
Non-Hodgkin lymphoma 50 (45–54)	250 (240-261)	436 (427-446)	564 (557–572)	178 (175-181)	78 (71-84)	82 (79-86)	118 (115–120)	156 (154-158)	434 (426-442)	18%	36%
0varian cancer 45 (43-46)	260 (250–271)	425 (408-442)	455 (443-468)	162 (160–165)	70 (68-72)	85 (82–89)	115 (110-119)	126 (123-130)	396 (389-403)	18%	32%
Kidney cancer 30 (29–31)	190 (177–202)	348 (334–361)	615 (607–623)	153 (150–155)	46 (45-48)	62 (58–66)	94 (90–98)	170 (168–173)	373 (367–379)	12%	46%
Lung cancer 21 (20–22)	250 (239–262)	403 (394-411)	364 (355-373)	133 (131–135)	33 (31-35)	82 (78-86)	109 (106-111)	101 (98–103)	325 (319–330)	10%	31%
Urinary bladder cancer 12 (11-13)	124 (115–133)	274 (268–279)	601 (591–610)	123 (121–125)	19 (17-20)	41 (38-44)	74 (72-75)	16 (164–169)	300 (295–304)	6%	55%
Stomach cancer 9 (8–9)	70 (65–75)	136 (128-144)	327 (297–357)	67 (64-71)	14 (13-15)	23 (21-25)	37 (34-39)	91 (82-99)	164 (155–173)	%6	55%
Hodgkin lymphoma 58 (57–60)	79 (72-87)	72 (66–77)	52 (47–57)	62 (60-64)	91 (89-94)	26 (23-28)	19 (18-21)	14 (13-16)	151 (147–155)	60%	%6
Head and neck cancer 14 (13-15)	115 (108-122)	150 (146–154)	138 (131–145)	57 (55–58)	22 (20–23)	38 (36–40)	41 (40-42)	38 (36-40)	138 (135-142)	16%	28%
Chronic lymphocytic leukaemia 4 or small lymphocytic lymphoma (3–4)	54 (49–59)	134 (126-141)	230 (219–242)	51 (49-52)	6 (5-7)	18 (16-19)	36 (34-38)	64 (61-67)	124 (120-128)	5%	52%

Articles

	Crude preval	Crude prevalence per 100 000	0			Number of pr	Number of prevalent cases (thousands)	housands)			Proportion of prevalent cases	of ses
	Age 0-54 years	Age 55-64 years	Age 65-74 years	Age ≥75 years	Allages	Age 0-54 years	Age 55-64 years	Age 65-74 years	Age ≥75 years	All ages	Age 0-54 years	Age ≥75 years
(Continued from previous page) Males												
All cancers	887 (877-897)	5999 (5765–6233)	14150 (13890-14410)	23103 (22851-23356)	4656 (4610-4702)	1425 (1409–1441)	1877 (1804-1951)	3358 (3296-3420)	4232 (4186-4278)	10 892 (10 785-11 000)	13%	39%
Prostate cancer	34 (32–36)	1617 (1498–1735)	6212 (6046–6379)	10776 (10591-10961)	1714 (1686–1741)	54 (51–58)	506 (469–543)	1474 (1435–1514)	1974 (1940–2008)	4008 (3944–4072)	1%	49%
Colorectal cancer	60 (59–62)	804 (764-844)	2070 (2024–2117)	4233 (4169–4297)	691 (682–699)	97 (94–100)	252 (239–264)	491 (480–502)	775 (764-787)	1615 (1595–1636)	6%	48%
Urinary bladder cancer	32 (30–34)	469 (445-493)	1293 (1251–1335)	2851 (2822–2880)	439 (433-445)	52 (48–55)	147 (139–154)	307 (297–317)	522 (517–528)	1027 (1013-1042)	5%	51%
Skin melanoma	87 (86-89)	363 (349-376)	709 (675-744)	1036 (1026–1046)	262 (257–266)	140 (138-142)	113 (109–118)	168 (160–176)	190 (188-192)	612 (602–621)	23%	31%
Kidney cancer	45 (44-46)	372 (338-406)	763 (745-781)	1232 (1203-1261)	255 (249–260)	72 (71-74)	116 (106–127)	181 (177–185)	226 (220-231)	595 (583–608)	12%	38%
Lung cancer	19 (18-19)	342 (321–362)	781 (754-807)	1075 (1032-1118)	222 (217–227)	30 (29–31)	107 (101-113)	185 (179-192)	197 (189–205)	519 (507–531)	6%	38%
Testicular cancer	193 (190–195)	336 (330-343)	210 (187–233)	153 (142-164)	211 (207–214)	310 (306-314)	105 (103-107)	50 (44–55)	28 (26–30)	493 (485–500)	63%	6%
Non-Hodgkin lymphoma	68 (67-70)	325 (321-328)	540 (533-547)	763 (736–789)	205 (202-207)	110 (107-112)	102 (100–103)	128 (126–130)	140 (135-145)	479 (473-485)	23%	29%
Head and neck cancer	29 (26–32)	347 (332-362)	405 (391-420)	302 (290–314)	131 (128–135)	47 (43-51)	109 (104-113)	96 (93-100)	55 (53-58)	307 (300–315)	15%	18%
Stomach cancer	10 (10-11)	112 (102-121)	252 (238–265)	552 (522–583)	91 (88-94)	16 (15-18)	35 (32–38)	60 (56–63)	101 (96-107)	212 (205–219)	8%	48%
Laryngeal cancer	7 (6-8)	163 (155-171)	312 (295–329)	391 (369-412)	89 (86–91)	11 (9-13)	51 (48–53)	74 (70–78)	72 (68–76)	207 (201–214)	5%	35%
Thyroid cancer	43 (42-44)	149 (142–156)	202 (195–208)	174 (167–181)	84 (82–85)	69 (67-71)	47 (45-49)	48 (46-49)	32 (31-33)	196 (192–199)	35%	16%
Chronic lymphocytic leukaemia or small lymphocytic lymphoma	8 (7-8)	89 (86–92)	222 (209–235)	411 (374-448)	72 (69–75)	12 (11-13)	28 (27–29)	53 (50–56)	75 (68-82)	168 (161–176)	7%	45%
Hodgkin lymphoma	61 (59–63)	108 (103-112)	93 (84-102)	63 (57–69)	71 (69–72)	98 (94–101)	34 (32–35)	22 (20–24)	12 (10-13)	165 (160-170)	59%	7%
Brain cancer	45 (44-47)	78 (73-82)	78 (63-93)	64 (50-78)	54 (52-57)	73 (70-75)	24 (23-26)	18 (15–22)	12 (9-14)	127 (122–133)	57%	%6
Crude prevalence proportion per 100 000 inhabitants and number of prevalent cases (thousands), with 95% CIs in parentheses. Percentage proportion of young (0-54 years) and older (75 years or older) prevalent cases. Data shown for cancers that had a prevalence higher than 50 per 100 000.	000 inhabitants 100.	and number of pre	evalent cases (thous	ands), with 95% Cls i	r parentheses. Perc	centage proportio	n of young (0-54	years) and older	(75 years or older	) prevalent cases. Dat	a shown for cai	ncers that had
Table 2: Estimated complete cancer prevalence in Europe (European	er prevalence i	n Europe (Europ		pool of 29 countries in EUROCARE-6) as of Jan 1, 2020, by cancer entity and age at prevalence date	RE-6) as of Jan 1,	, 2020, by cance	r entity and ag	e at prevalence	e date			

 $5 \cdot 0\%$  of the resident population (4961 [95% CI 4931–4992] per 100 000 population; table 1). The same proportion and a slightly lower number (22 347 thousand [95% CI 22 210–22 483]) were estimated for EU27 (447 320 thousand inhabitants).

Cancer survivors were more frequently female than male (in the European pool: 12818 thousand [95% CI 12720-12917] vs 10892 thousand [10785-11000]; 5.3% [95% CI 5·2-5·3] vs 4·7% [4·6-4·7]) in terms of crude proportions, although the estimated ratio of female to male cases varied between countries from 1.0 to 1.7 because of differences in cancer case-mix and demographic structure (table 1). Estimated crude proportion of cancer prevalence was higher in central Europe (5601 [95% CI 5541–5661] per 100000), southern Europe (5198 [5146–5250] per 100000), and northern Europe (5080 [5034-5126] per 100000); intermediate in Ireland and the UK (4156 [4084-4228] per 100000); and lowest in eastern Europe (3476 [3451-3502] per 100000). Between-country differences in crude prevalence were estimated to be even wider, ranging from 3562 (95% CI 3499-3626) per 100000 in Poland to 6338 (6177-6498) per 100000 in Italy for females, and from 2372 (2321-2422) per 100000 in Bulgaria to 5692 (5512-5873) per 100000 in Germany for males. When comparing age-standardised prevalence estimates, heterogeneity was reduced and some countries ranked differently, as in the case of Italy and Germany, both of which have a high proportion of people aged 65 years or older

Leading cancer types among survivors differed remarkably by sex, reflecting different incidence and survival profiles (table 2). Breast and prostate cancers were estimated to account for approximately 40% of all cancer survivors: 43.2% in females (5539 thousand [95% CI 5486-5592]) and 36.8% in males (4008 thousand [3944-4072]), respectively. Colorectal cancer was the second most common tumour in both sexes, with a higher crude prevalence in males (691 [95% CI 682-699] per 100000) than in females (564 [557-572] per 100000). Corpus uterine cancer (932 thousand [95% CI 918-947]), cervical uterine cancer (625 thousand [610-641]), ovarian cancer (396 thousand [389-403]), skin melanoma (779 thousand [770–788]), thyroid cancer (734 thousand [724–744]), and non-Hodgkin lymphomas (434 thousand [426-442]) accounted for a further third of prevalent cases among female survivors. In male survivors, a third of prevalent cases were diagnosed with urinary bladder cancer (1027 thousand [95% CI 1013-1042]), kidney cancer (595 thousand [583-608]), skin melanoma (612 thousand [602-621]), lung cancer (519 thousand [507-531]), and testicular cancer (493 thousand [485-500]).

The majority of cancer survivors in Europe were estimated to be 65 years or older: 7955 thousand ( $62 \cdot 1\%$ ) of 12818 thousand female survivors and 7590 thousand ( $69 \cdot 7\%$ ) of 10892 thousand male survivors (table 2). People aged 75 years or older comprised a substantial

proportion of those living after a diagnosis of colorectal, corpus uterine, prostate, urinary bladder, stomach, and female kidney cancer, and chronic lymphocytic leukaemia or small lymphocytic lymphoma. An estimated 3741 thousand (95% CI 3701–3781) cancer survivors were younger than 55 years and comprised 15.8% of all prevalent cases (2316 thousand [18.1%; 95% CI 2291–2341] were female and 1425 thousand [13.1%; 1409–1441] were male). The majority of diagnoses (about 60%) in this age group were for early-onset cancers that have a good prognosis, such as Hodgkin lymphoma or testicular cancer. The distribution by age and sex for cancer sites with lower prevalence is shown in the appendix (p 24).

The complete cancer prevalence estimates differed substantially between countries. In female survivors, crude prevalence proportion was more than two times higher in the highest prevalence country versus the lowest prevalence country for all the top eight cancers: eg, breast (crude prevalences ranging from 1268 [95% CI 1246-1289] per 100 000 in Poland to 2924 [2846-3002] per 100 000 in Belgium), colorectal (339 [325-353] per 100 000 in Poland to 744 [722-766] per 100000 in Italy), and corpus uterine cancer (249 [232-266] per 100000 in Ireland to 609 [591–626] per 100 000 in Lithuania; figure 1; appendix pp 16–19). The differences between countries were even greater for tumours with substantial incidence dynamics and geographical variability, such as thyroid cancer (<130 cases per 100000 in Denmark and the Netherlands, and in all countries in the Ireland and UK macro region, and >700 per 100000 in Italy and Cyprus), skin melanoma (83 per 100000 in Bulgaria and 700 per 100000 in Denmark), and cervical uterine cancer (from <100 per 100 000 in Malta and Finland to >550 per 100 000 in Bulgaria and Lithuania).

Substantial differences (4–5 times) across countries were also estimated for male prevalence of prostate cancer (from 487 [95% CI 396–577] per 100 000 in Bulgaria to 2424 [2291–2556] per 100 000 in France) and urinary bladder cancer (from 156 [145–168] per 100 000 in England to 783 [751–815] per 100 000 in Italy; figure 1; appendix pp 20–23). As for female survivors, striking differences were estimated for skin melanoma in males (from 60 [95% CI 57–62] per 100 000 in Bulgaria to 505 [500–511] per 100 000 in Denmark). Differences in cancer prevalence between countries largely reflect differences in incidence risk, as shown by the high goodness of fit of the linear correlation between country-specific prevalence profiles in 2020 and crude incidence rates in previous years for the top eight cancers (appendix pp 30–31).

Cancer prognosis, median age at onset, and previous incidence time trends (decreasing vs increasing) were the main factors influencing prevalence patterns by disease duration. In 2020, 14850 thousand (95% CI 14681–15018) people were estimated to be alive more than 5 years after diagnosis and 9099 thousand (8909–9288) people were estimated to be alive more

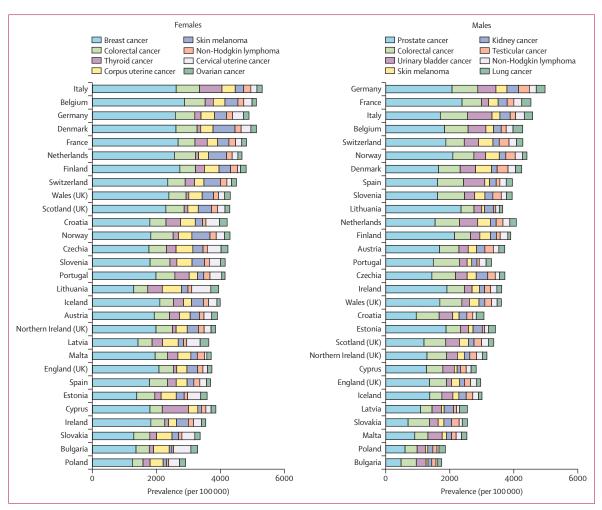


Figure 1: Estimated complete prevalence proportion as of Jan 1, 2020, by sex and country

Data are shown for the eight cancers with the highest crude prevalence. Countries in the EUROCARE-6 dataset are ranked by complete cancer prevalence for all cancers.

than 10 years after diagnosis, representing an increasing proportion of the cancer survivor population. Overall, in early 2020, the number of female survivors in the European pool diagnosed with cancer within the past 2 years was estimated to be 2037 thousand (95% CI 1971-2104) or within the past 2-5 years was 2412 thousand (2330-2494; figure 2). Long-term survivors (ie, living with cancer for more than 5 years) accounted for 8368 thousand (65 · 3%) of 12818 thousand prevalent female cases, of whom 2757 thousand (21.5%; 95% CI 2682-2832) are estimated to have been living with a diagnosis for more than 5 years to 10 years, 3233 thousand (25.2%; 3132-3334) for more than 10 years to 20 years, and 2378 thousand (18.5%; 2249-2507) for a duration longer than 20 years. Similar distributions are estimated for females diagnosed with breast cancer, colorectal cancer, corpus uterine cancer, thyroid cancer, kidney cancer, urinary bladder cancer, non-Hodgkin lymphoma, and skin melanoma. 5611 thousand (43.8%; 95% CI 5497-5726) of 12 818 thousand females were very long-term survivors (more than 10 years since diagnosis). The proportion of very long-term survivors was highest for cervical uterine cancer (447 345 [71.5%] of 625 179) and Hodgkin lymphoma (97 166 [64.3%] of 151 166), and lowest for lung cancer (60 188 [18.5%] of 324729).

Overall, in early 2020, in the European pool, the number of males living for up to 2 years after a cancer diagnosis was 2071 thousand (95% CI 2015–2127) and 2–5 years after a cancer diagnosis was 2340 thousand (2252–2428; figure 2). Males surviving more than 5 years after diagnosis represented 59.5% of all prevalent male cases (6481 thousand [95% CI 6353–6608] of 10892 thousand). Among the latter, 2994 thousand (27.5%; 95% CI 2868–3119) were estimated to have been living with a cancer diagnosis for more than 5 years to 10 years, 2312 thousand (21.2%; 2169–2454) for more than 10 years to 20 years, and 1175 (10.8%; 1032–1319) for a duration longer than 20 years. Similar proportions were estimated for the tumours with the

highest prevalence in men (prostate, colorectal, urinary bladder, skin melanoma, kidney, and non-Hodgkin lymphoma). The proportion of males surviving more than 10 years was  $32 \cdot 0\%$  (3487 thousand [95% CI 3336–3638] of 10892 thousand). The latter proportion for males diagnosed with Hodgkin lymphoma and testicular cancer was more than 60% (103 thousand of 165 thousand and 312 thousand of 493 thousand, respectively), whereas it was less than 25% (119 thousand of 519 thousand and 955 thousand of 4008 thousand, respectively) for those diagnosed with lung and prostate cancer.

The estimated total number of cancer survivors in the European pool has increased on average by 3.5% per year from 2010 to 2020, from 16 805 thousand (95% CI 16798–16 813) on Jan 1, 2010, to 23710 thousand (23565–23857) on Jan 1, 2020, a relative change of 41% (figure 3). A similar increase (37%) is estimated for the crude prevalence (from 3615 cases [95% CI 3613–3617] per 100 000 to 4961 [4931–4992] per 100 000). The age-standardised prevalence is estimated to have increased less steeply (24%, from 3864 [95% CI 3862–3866] per 100 000 to 4783 [4754–4813] per 100 000, because it is not affected by demographic changes.

The prevalence of cases living within 5 years after a diagnosis is estimated to have increased by 28% between 2010 (6932 thousand [95% CI 6927–6937]) and 2020 (8861 thousand [95% CI 8835–8887]). Conversely, the number of people living for more than 10 years after diagnosis is estimated to have increased by 50% over the same period (from 6047 thousand [95% CI 6037–6057] to 9099 thousand [8909–9288]) and is expected to become an increasingly important proportion of all cancer survivors in the near future.

The impact of demographic ageing on the changes of cancer prevalence in 2010-20, compared with the dynamics of incidence and survival, is shown in figure 4 (details in the appendix p 25). The number of survivors from all cancers is predicted to increase by 45.9% in males, of which 26.9% is attributable to incidence and survival changes and 19.0% to ageing. The relative percentage increase is predicted to be lower in females (37.3%) than in males, with a smaller effect of ageing (12.2%), because of the different case-mix and lower average age at onset. The cancers with increasing incidence and survival showed the steepest relative percentage increase in the number of prevalent cases: skin melanoma (77.9% in males and 55.3% in females), female lung cancer (84.4%), thyroid cancer (76.8% in males and 63.6% in females), and prostate cancer (70.9%). For these cancer sites, incidence and survival changes had a much greater impact (2-7 times) than the ageing of the population between 2010 and 2020. For smoking-related cancers (lung, head and neck, and larynx), the increase in prevalence is estimated to be more substantial in females, in line with less favourable incidence trends in females than in males. Prevalence

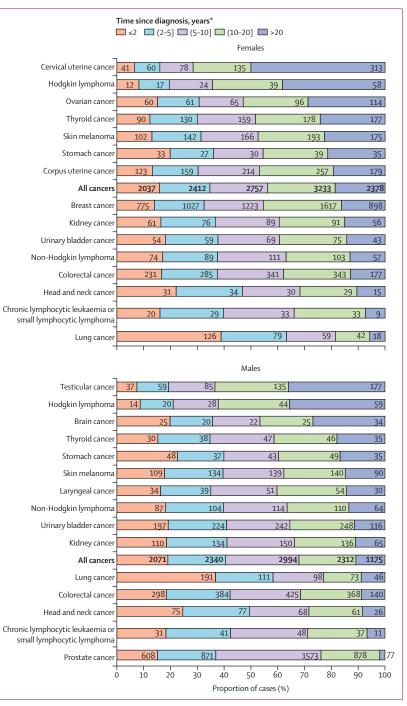


Figure 2: Complete number of prevalent cancer cases (in thousands) by sex and disease duration in Europe (European pool of 29 countries in EUROCARE-6) as of Jan 1, 2020

Cancer sites with crude prevalence proportion higher than 50 per 100 000 are shown. Values ordered by decreasing proportion of cases surviving 20 years or more after diagnosis. \*Round brackets indicate excluded endpoints, whereas square brackets indicate included endpoints.

was estimated to decrease for cervical uterine cancer only (-0.3%), but the increase was also limited for other tumours with declining incidence, such as stomach cancer (10.6% for males and 11.9% for females) and

male laryngeal cancer (2.9%). In the absence of demographic ageing, the prevalence of these cancers would decrease. Demographic changes have a minimal effect on the prevalence increase for juvenile cancers, such as testicular cancer, brain cancer, or Hodgkin lymphoma (1–4%).

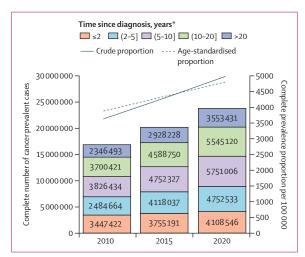


Figure 3: Change in estimated complete cancer prevalence between Jan 1, 2010, and Jan 1, 2020, in Europe (European pool of 29 countries in EUROCARE-6)

Overall number of prevalent cases by disease duration in years and complete crude and age-standardised proportions per 100 000 (European Standard Population 2013). \*Round brackets indicate excluded endpoints, whereas square brackets indicate included endpoints.

## Discussion

We estimated that, in early 2020, an average of 5% of the European population had a recent or distant history of cancer. Most were female, older than 65 years, and living more than 5 years after a cancer diagnosis. Overall, 38% of all prevalent cases in Europe were living more than 10 years after a cancer diagnosis (44% female and 32% male). These proportions are lower than those estimated in the USA in Jan 1, 2020 (47% overall, 50% in women, and 44% in males)<sup>11</sup> using the same methodology and similar population-based data sources. A lower long-term cancer prevalence in European populations is consistent with the better prognosis generally reported for patients in the USA than in Europe.<sup>12</sup>

Breast (in females), prostate (in males), and colorectal cancers (in both sexes combined) alone account for 53% of all cancer survivors. Less common tumours that occur at younger ages (skin melanoma, thyroid cancer, testicular cancer, and cervical cancer) are more frequent in cancer survivors than common fatal tumours diagnosed in older people (pancreatic, oesophageal, and liver), which did not reach crude prevalence estimates of 0.05%.

Our study also highlights the large differences between countries in cancer prevalence, which are much greater than those of cancer incidence or mortality. Incidence is by far the most important determinant of geographical variation, followed by differences in survival and demographics, the latter partly inflating the crude proportions in countries with an older population.<sup>13</sup>

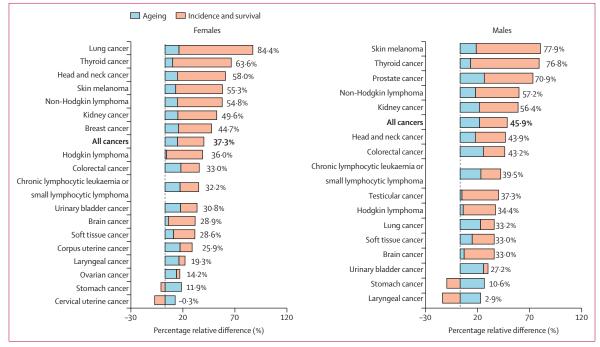


Figure 4: Estimated percentage relative difference for the period 2010-20 in complete prevalence counts, by cancer and sex, in Europe (European pool of 29 countries in EUROCARE-6)

Percentage difference is decomposed by determinant: demographic ageing or incidence and survival dynamics. Cancer sites with prevalence higher than 50 per 100 000 for both sexes combined, or in males and females separately for sex-specific cancers.

Variations between countries reflect both real differences in incidence risk (as in the case of cutaneous melanoma or lung cancer) and different levels of diagnostic intensity, screening, and overdiagnosis, as in the case of thyroid cancer<sup>14</sup> or prostate cancer.<sup>15</sup> Country-specific estimates of complete prevalence are consistent with limited-duration prevalence estimates available in some countries (same order of magnitude and higher values). Estimates for urinary bladder and brain cancers are not fully comparable across Europe because of missing non-malignant cases for some registries. These missing data explain, for example, the particularly low estimates for male urinary bladder cancer in France and England. The selected population coverage in countries with regional registration (from 10% in France to a maximum of 20% in Switzerland) might limit the representativeness of our estimates at country level. To contain this limitation in Italy, where within-country heterogeneity is particularly relevant, the national estimate was obtained by combining separate estimates for registries in the centre-north and south.

Projections to 2020 by country relied on prevalence time trends over the latest 3-year period available (2011–13). Validation against NORDCAN observations<sup>10</sup> guided the choice of time base for projections and confirmed the validity of assuming linear trends. Trends in cancer prevalence are, indeed, rather smooth over time, because the number of alive incident cases is cumulated year after year. However, deviations from linearity can occur when incidence changes sharply, as was the case with prostate cancer,<sup>15</sup> which peaked in some European countries around 2013 and then levelled off.

We have estimated a remarkable increase in the number of cancer survivors in the decade 2010-20, reflecting an increase for all cancers except those with a more frequent declining incidence risk (stomach, cervical uteri, and male larynx). This is probably not due to an increase in the general population, which grew by only 3% over the same period, but is partly due to the ageing of the population, with the number of people aged 65 years or older in Europe increasing by 20% between 2010 and 2020. However, we found that trends in incidence and survival had a greater or equal effect on prevalence growth than demographic changes. The number of cancer survivors increased faster in males than in females, largely due to the increase in incidence of prostate cancer, which was observed at different rates in all countries.

Survivorship care services are increasingly being advocated to improve cancer care throughout the life course. We have extended the estimation of cancer prevalence beyond the traditional 5-year prevalence and found that long-term survivors are an increasing population that should be focused on. They include people who are cured and those who will die from the disease. Among people who are cured, some will have no further sequelae, whereas others will still need to be monitored for late sequelae due to toxicity and long-term complications of cancer therapy or increased risk of secondary malignancies.

Whenever a cure with no further sequelae is possible, the time to cure—after which the risk of death of patients reaches that of the general population without cancer can be estimated according to key prognostic factors to complement and better qualify complete cancer prevalence statistics.<sup>16</sup>

Estimates on complete cancer prevalence tell us how prevalent cases are distributed by disease duration and what their demographic characteristics are. They are useful for quantifying the target population for interventions aimed at specific subpopulations of survivors, but not for deriving information on their actual health status as a function of the time since diagnosis.

European prevalence completeness indexes were computed using incidence and relative survival observations from a pool of selected long-standing registries. This approach ensured robust estimates over the long term. A larger pool would have increased the population coverage at the cost of reduced follow-up. All European areas are represented in the selected pool used to derive European R-indexes, and their performance has been positively validated against registry-specific observed prevalence in Europe and against alternative indexes (US R-indexes).<sup>3</sup>

Projections to 2020 assume a constant linear trend in prevalence from 2013 onwards. This assumption cannot capture deviations from linearity occurring after 2013 due to epidemiological trends or changes in cancer control strategies. Validation in the Nordic countries showed these limits for cancers with declining prevalence (cervix and stomach) and, to a lesser extent, for lung and colon cancers.

Our projections are up to Jan 1, 2020, and represent a pre-COVID-19 baseline. Changes in cancer incidence (reduced diagnostic capacity), outcome (delayed referral), and population age structure (high mortality among older people) that occurred during the COVID-19 pandemic emergency do not allow a priori assumptions of a stable prevalence trend after 2020. More recent data and new assessments will be needed to draw more firm conclusions.

The broad population coverage, including the EU27, the UK, and the European Free Trade Association countries, and the projections to early 2020 are major strengths. Complete cancer prevalence is indeed not routinely calculated in all countries, and the available estimates in Europe are not up to date<sup>17</sup> or are limited to specific countries.<sup>18-20</sup>

To optimise the accuracy and comparability of our estimates, we used the completeness index method,<sup>8,9</sup> one of the most validated methods for calculating complete and limited-duration prevalence using maximum available information observed by cancer registries. The method is systematically applied in the USA, where complete prevalence statistics are published

annually,<sup>11</sup> and specific software (COMPREV) for implementing the method is distributed. Compared with international cancer prevalence estimates<sup>1,21</sup> (including those available on the Global Cancer Observatory), the completeness index method is more firmly based on observations. Estimates are registry-specific and derived from observed prevalence at the maximum available duration. For example, 5-year prevalence estimates are fully observed until 2013 and then projected. In addition, the completeness correction decreases with increasing registration length. This feature ensures the highest possible adherence of estimates to observations.

The distribution by short, long, and very long disease duration is an additional strength of our study. Although there is a growing body of evidence on the problems and unmet needs of cancer survivors,22 little is known about their actual numbers and characterisation, especially in the long term. Research on the quality of life of longterm survivors after cancer, often based on representative samples from cancer registry data,23,24 highlights a wide range of issues that point to integrated models of care, with an increasing role for patient-centred care and community medicine.25 Information on cancer prevalence by disease duration is crucial not only at the health-care level to plan patient care and rehabilitation, but also at the societal level, to assess the impact of policies to mitigate the socioeconomic consequences of the disease, such as employment discrimination or financial toxicity.<sup>26,27</sup>

The large and growing burden of cancer on the European population confirms the need to strengthen cancer prevention measures, as envisaged in Europe's Beating Cancer Plan and related action plans. Primary prevention and early diagnosis are the most effective tools to reduce in the coming years the burden of cancer and improve the quality of life of patients.

People living after a juvenile cancer have been shown to be an important component of long-term cancer survivors. Addressing the health and socioeconomic impact of cancer on this vulnerable subpopulation is particularly valuable. Initiatives such as the survivorship passport or the legislation on the right to be forgotten<sup>26</sup> should be pursued in all countries.

Complete information on cancer prevalence at country level is needed in Europe to develop evidence-based policies on cancer survivorship. This information should be systematically integrated into the European Cancer Information System. Our study shows that an effective way to ensure accurate and comparable estimates of complete cancer prevalence at national level is to jointly analyse data from European registries. Continuity in these collaborative studies with high added value for Europe is essential to make prevalence estimates available on a regular and systematic basis. Future developments in this area should incorporate the analysis of cured cancer survivors and time to cure, to provide robust epidemiological evidence useful for

responsibly optimising follow-up care guidelines and recommendations.

#### Contributors

RDA drafted the manuscript and designed and coordinated the study. ED carried out the study and analysed the prevalence data. SR coordinated the data quality checks and the preparation of the study database. PB, SR, and MS prepared the registry-specific life tables. SR and MS implemented the procedures to check the raw data and to generate the SEER\*Stat study database. ED, SR, and LV estimated and validated the European prevalence completeness indexes. LDM, SG, AK, MG, KP, and KI contributed to validate country-specific prevalence estimates. XT, AK, MDCL, KI, MBl, KP, RG, MG, GR, MBe, LB, LDM, SG, and SR provided advice and revised the results. RDA, ED, SR, LV, PB, and MS accessed and verified the underlying study data. The EUROCARE-6 Working Group collected, prepared, and transmitted raw data for the study database, corrected data after quality controls, checked the results of the analyses, and revised the final draft of the manuscript. All authors interpreted results, contributed to writing the manuscript, reviewed, and approved the final version. All authors had full access to all the data in the study and had final responsibility for the decision to submit for publication.

#### **Declaration of interests**

We declare no competing interests.

#### Data sharing

The detailed results on cancer prevalence by cancer site, country, age, and disease duration will be available on the European Cancer Information System website with publication. The European completeness indexes of cancer prevalence estimated for this Article can be shared upon reasonable request to the corresponding author.

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