



Supporting Information

Supplementary methods and results

**This appendix was part of the submitted manuscript and has been peer reviewed.
It is posted as supplied by the authors.**

Appendix to: Goldsbury DE, Haywood P, Pearce A, et al. Out-of-pocket health care expenses for people with and without cancer, New South Wales, 2020: a cross-sectional study. *Med J Aust* 2024; doi: 10.5694/mja2.52367.

Table 1. Questions asked in the 45 and Up Study follow-up questionnaire (2020)*

In the past 12 months, about how much have you spent out-of-pocket on YOUR healthcare?

Please EXCLUDE costs covered by Medicare or private health insurance.

- *Medications (prescription or over the counter)*
- *Doctors, specialists (e.g. GP, oncologist)*
- *Medical tests (e.g. x-rays, pathology)*
- *Hospitalisation/outpatient (e.g. surgery)*
- *Dental care*
- *Allied health care (e.g. physiotherapy)*
- *Other complementary/alternative treatments (e.g. naturopathy)*
- *Medical equipment (e.g. crutches)*
- *Practical/travel (e.g. parking, accommodation)*
- *Home/other modifications (e.g. ramps)*
- *Any other healthcare costs*

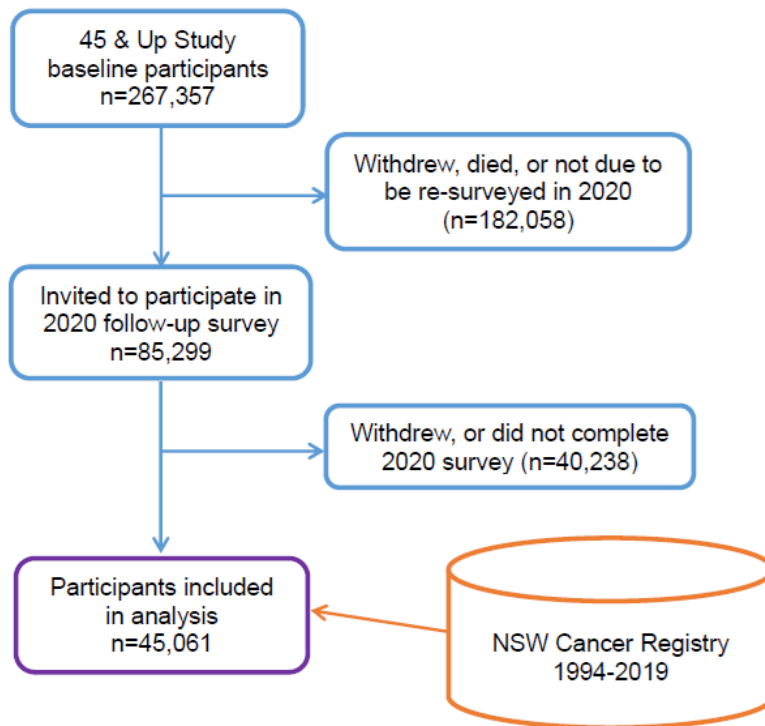
[Response options for each cost type: N/A; \$0; \$1-\$250; \$251-\$1000; \$1001-\$10,000; More than \$10,000]

In the past 12 months, about how much have you spent out-of-pocket on YOUR healthcare for all of the above combined?

[Response options: N/A; \$0; \$1-\$250; \$251-\$1000; \$1001-\$10,000; \$10,001-\$25,000; More than \$25,000; Unsure]

* Source: <https://www.saxinstitute.org.au/solutions/45-and-up-study/use-the-45-and-up-study/data-and-technical-information>; viewed June 2023).

Figure 1. Participant selection flow and data sources*



* 45 and Up Study participants are followed up approximately every five years. At the start of each 5-year follow-up period, all remaining contactable participants who have not died and have not withdrawn are split into recruitment groups, or “phases” of the next wave; in this case, into three groups. In general, selection is based on the baseline recruitment date in order to achieve the 5-year gap between surveys.

Table 2. Out-of-pocket expenses in the preceding twelve months for 45,061 respondents to the 2020 45 and Up questionnaire, overall and by cost type and cancer status*

Cost type	Number	Out-of-pocket expenses					
		None	\$1-250	\$251-1000	\$1000-10,000	>\$10,000	Unsure/missing
Overall							
All participants	45,061	1319 (3%)	5490 (12%)	15,678 (35%)	17,947 (40%)	1289 (3%)	3338 (7%)
No cancer	37,145	1124 (3%)	4680 (13%)	13,106 (35%)	14,600 (39%)	992 (3%)	2643 (7%)
Cancer >2 years	7,055	181 (3%)	757 (11%)	2335 (33%)	2944 (42%)	223 (3%)	615 (9%)
Cancer ≤2 years	861	14 (2%)	53 (6%)	237 (28%)	403 (47%)	74 (9%)	80 (9%)
Medications							
All participants	45,061	3716 (8%)	21,885 (49%)	14,367 (32%)	2747 (6%)	33 (<1%)	2313 (5%)
No cancer	37,145	3257 (9%)	18,347 (49%)	11,549 (31%)	2151 (6%)	23 (<1%)	1818 (5%)
Cancer >2 years	7,055	423 (6%)	3195 (45%)	2482 (35%)	522 (7%)	5 (<1%)	428 (6%)
Cancer ≤2 years	861	36 (4%)	343 (40%)	336 (39%)	74 (9%)	5 (1%)	67 (8%)
Doctors/specialists							
All participants	45,061	8820 (20%)	12,970 (29%)	14,267 (32%)	4564 (10%)	157 (<1%)	4283 (10%)
No cancer	37,145	7544 (20%)	11,013 (30%)	11,478 (31%)	3507 (9%)	101 (<1%)	3502 (9%)
Cancer >2 years	7,055	1175 (17%)	1808 (26%)	2495 (35%)	862 (12%)	24 (<1%)	691 (10%)
Cancer ≤2 years	861	101 (12%)	149 (17%)	294 (34%)	195 (23%)	32 (4%)	90 (10%)
Medical tests							
All participants	45,061	20,950 (46%)	9366 (21%)	5728 (13%)	862 (2%)	12 (<1%)	8143 (18%)
No cancer	37,145	17,546 (47%)	7773 (21%)	4546 (12%)	609 (2%)	12 (<1%)	6659 (18%)
Cancer >2 years	7,055	3118 (44%)	1431 (20%)	997 (14%)	184 (3%)	0	1325 (19%)
Cancer ≤2 years	861	286 (33%)	162 (19%)	185 (21%)	69 (8%)	0	159 (18%)
Hospitalisation/outpatient							
All participants	45,061	27,767 (62%)	1969 (4%)	3605 (8%)	1668 (4%)	129 (<1%)	9923 (22%)
No cancer	37,145	23,255 (63%)	1528 (4%)	2835 (8%)	1299 (3%)	88 (<1%)	8140 (22%)
Cancer >2 years	7,055	4139 (59%)	376 (5%)	647 (9%)	270 (4%)	20 (<1%)	1603 (23%)
Cancer ≤2 years	861	373 (43%)	65 (8%)	123 (14%)	99 (11%)	21 (2%)	180 (21%)
Dental care							
All participants	45,061	10,772 (24%)	11,607 (26%)	13,466 (30%)	4470 (10%)	159 (<1%)	4587 (10%)
No cancer	37,145	8744 (24%)	9693 (26%)	11,203 (30%)	3713 (10%)	134 (<1%)	3658 (10%)
Cancer >2 years	7,055	1803 (26%)	1716 (24%)	2019 (29%)	677 (10%)	25 (<1%)	815 (12%)
Cancer ≤2 years	861	225 (26%)	198 (23%)	244 (28%)	80 (9%)	0	114 (13%)
Allied health care							
All participants	45,061	21,716 (48%)	8584 (19%)	5347 (12%)	680 (2%)	7 (<1%)	8727 (19%)
No cancer	37,145	17,932 (48%)	7115 (19%)	4415 (12%)	574 (2%)	7 (<1%)	7102 (19%)

Cost type	Number	Out-of-pocket expenses					Unsure/missing
		None	\$1-250	\$251-1000	\$1000-10,000	>\$10,000	
Cancer >2 years	7,055	3398 (48%)	1309 (19%)	830 (12%)	91 (1%)	0	1427 (20%)
Cancer ≤2 years	861	386 (45%)	160 (19%)	102 (12%)	15 (2%)	0	198 (23%)
Other complementary/ alternative treatment							
All participants	45,061	28,251 (63%)	3217 (7%)	2043 (5%)	368 (1%)	5 (<1%)	11,177 (25%)
No cancer	37,145	23,270 (63%)	2735 (7%)	1763 (5%)	320 (1%)	5 (<1%)	9052 (24%)
Cancer >2 years	7,055	4456 (63%)	433 (6%)	240 (3%)	42 (1%)	0	1884 (27%)
Cancer ≤2 years	861	525 (61%)	49 (6%)	40 (5%)	6 (1%)	0	241 (28%)
Medical equipment							
All participants	45,061	30,647 (68%)	2133 (5%)	563 (1%)	268 (1%)	14 (<1%)	11,436 (25%)
No cancer	37,145	25,447 (69%)	1720 (5%)	436 (1%)	217 (1%)	9 (<1%)	9316 (25%)
Cancer >2 years	7,055	4646 (66%)	374 (5%)	113 (2%)	46 (1%)	5 (<1%)	1871 (27%)
Cancer ≤2 years	861	554 (64%)	39 (5%)	14 (2%)	5 (1%)	0	249 (29%)
Practical/travel							
All participants	45,061	26,591 (59%)	5993 (13%)	1248 (3%)	349 (1%)	14 (<1%)	10,866 (24%)
No cancer	37,145	22,313 (60%)	4670 (13%)	951 (3%)	269 (1%)	14 (<1%)	8928 (24%)
Cancer >2 years	7,055	3921 (56%)	1103 (16%)	242 (3%)	62 (1%)	0	1727 (24%)
Cancer ≤2 years	861	357 (41%)	220 (26%)	55 (6%)	18 (2%)	0	211 (25%)
Home/other modifications							
All participants	45,061	32,016 (71%)	634 (1%)	440 (1%)	234 (1%)	60	11,677 (26%)
No cancer	37,145	26,574 (72%)	479 (1%)	330 (1%)	191 (1%)	44 (<1%)	9527 (26%)
Cancer >2 years	7,055	4873 (69%)	134 (2%)	94 (1%)	36 (1%)	16 (<1%)	1902 (27%)
Cancer ≤2 years	861	569 (66%)	21 (2%)	16 (2%)	7 (1%)	0	248 (29%)
Other health care costs							
All participants	45,061	28,541 (63%)	2233 (5%)	1107 (2%)	429 (1%)	26 (<1%)	12,725 (28%)
No cancer	37,145	23,723 (64%)	1845 (5%)	904 (2%)	334 (1%)	18 (<1%)	10,321 (28%)
Cancer >2 years	7,055	4337 (61%)	341 (5%)	181 (3%)	80 (1%)	8 (<1%)	2108 (30%)
Cancer ≤2 years	861	481 (56%)	47 (5%)	22 (3%)	15 (2%)	0	296 (34%)

* See also Box 1 in the main article. Row percentages may not add to 100% because of rounding. To conserve privacy, selected cells including fewer than five people have been set to 0 and the surrounding cells adjusted to maintain totals.

Table 3. Higher overall out-of-pocket costs by characteristics of participants

Characteristic	Total number	Out-of-pocket costs >\$1000		Out-of-pocket costs >\$10,000	
		Number	Proportion (95% CI)	Number	Proportion (95% CI)
All respondents	45,061	19,236	42.7% (42.2-43.2%)	1289	2.9% (2.7-3.0%)
<u>Age at follow-up</u>					
<60 years	3,403	1,505	44.2% (42.6-45.9%)	69	2.0% (1.6-2.5%)
60-69	19,079	8,848	46.4% (45.7-47.1%)	514	2.7% (2.5-2.9%)
70-79	15,603	6,468	41.5% (40.7-42.2%)	501	3.2% (2.9-3.5%)
80+	6,976	2,415	34.6% (33.5-35.7%)	205	2.9% (2.5-3.3%)
<u>Sex</u>					
Female	25,213	10,346	41.0% (40.4-41.6%)	672	2.7% (2.5-2.9%)
Male	19,848	8,890	44.8% (44.1-45.5%)	617	3.1% (2.9-3.4%)
<u>Accessibility/Remoteness of residence</u>					
Major cities	22,387	10,120	45.2% (44.6-45.9%)	738	3.3% (3.1-3.5%)
Inner regional	16,176	6,523	40.3% (39.6-41.1%)	370	2.3% (2.1-2.5%)
Outer regional/Remote/Very remote	4,738	1,788	37.7% (36.4-39.1%)	123	2.6% (2.1-3.0%)
Missing	1,760	805	45.7% (43.4-48.1%)	58	3.3% (2.5-4.1%)
<u>Socioeconomic quintile of residence</u>					
Most disadvantaged	7,190	2,514	35.0% (33.9-36.1%)	153	2.1% (1.8-2.5%)
Quintile 2	8,696	3,335	38.4% (37.3-39.4%)	205	2.4% (2.0-2.7%)
Quintile 3	8,282	3,418	41.3% (40.2-42.3%)	202	2.4% (2.1-2.8%)
Quintile 4	8,278	3,595	43.4% (42.4-44.5%)	222	2.7% (2.3-3.0%)
Least disadvantaged	10,447	5,397	51.7% (50.7-52.6%)	441	4.2% (3.8-4.6%)
Missing	2,168	977	45.1% (43.0-47.2%)	66	3.0% (2.3-3.8%)
<u>Household income</u>					
<\$30,000	9,649	3,093	32.1% (31.1-33.0%)	220	2.3% (2.0-2.6%)
\$30,000 - <\$50,000	7,744	3,071	39.7% (38.6-40.7%)	182	2.4% (2.0-2.7%)
\$50,000 - <\$90,000	11,172	5,246	47.0% (46.0-47.9%)	348	3.1% (2.8-3.4%)
\$90,000 - <\$120,000	3,515	1,850	52.6% (51.0-54.3%)	119	3.4% (2.8-4.0%)
\$120,000+	6,090	3,315	54.4% (53.2-55.7%)	214	3.5% (3.1-4.0%)
Unknown/Prefer not to answer	6,891	2,661	38.6% (37.5-39.8%)	206	3.0% (2.6-3.4%)
<u>Health insurance</u>					
Private insurance	32,897	15,777	48.0% (47.4-48.5%)	1088	3.3% (3.1-3.5%)
Department of Veterans' Affairs	657	83	12.6% (10.1-15.2%)	5	0.8% (0.1-1.4%)

Characteristic	Total number	Out-of-pocket costs >\$1000		Out-of-pocket costs >\$10,000	
		Number	Proportion (95% CI)	Number	Proportion (95% CI)
Healthcare card	6,458	1,755	27.2% (26.1-28.3%)	110	1.7% (1.4-2.0%)
No health insurance	5,049	1,621	32.1% (30.8-33.4%)	86	1.7% (1.3-2.1%)
<u>Highest education (baseline)</u>					
No school certificate	2,626	699	26.6% (24.9-28.3%)	53	2.0% (1.5-2.6%)
School certificate	7,751	2,766	35.7% (34.6-36.8%)	196	2.5% (2.2-2.9%)
High school completed	4,010	1,642	40.9% (39.4-42.5%)	102	2.5% (2.1-3.0%)
Certificate/Diploma/Trade/Apprenticeship	14,851	6,150	41.4% (40.6-42.2%)	414	2.8% (2.5-3.1%)
University+	15,430	7,848	50.9% (50.1-51.7%)	511	3.3% (3.0-3.6%)
Unknown/No response	393	131	33.3% (28.7-38.0%)	13	3.3% (1.5-5.1%)
<u>Work status</u>					
Paid work/Self-employed	12,817	5,976	46.6% (45.8-47.5%)	357	2.8% (2.5-3.1%)
Retired	28,652	11,913	41.6% (41.0-42.1%)	800	2.8% (2.6-3.0%)
Other (including unemployed, unpaid)	3,056	1,232	40.3% (38.6-42.1%)	119	3.9% (3.2-4.6%)
Missing	536	115	21.5% (18.0-24.9%)	13	2.4% (1.1-3.7%)
<u>Marital status</u>					
Married/De Facto/Partner	32,923	14,686	44.6% (44.1-45.1%)	981	3.0% (2.8-3.2%)
No partner	11,868	4,487	37.8% (36.9-38.7%)	300	2.5% (2.2-2.8%)
Missing	270	63	23.3% (18.3-28.4%)	8	3.0% (0.9-5.0%)
<u>Smoking status</u>					
Never	28,594	12,206	42.7% (42.1-43.3%)	828	2.9% (2.7-3.1%)
Former	14,907	6,494	43.6% (42.8-44.4%)	421	2.8% (2.6-3.1%)
Current	1,082	398	36.8% (33.9-39.7%)	29	2.7% (1.7-3.6%)
Unknown/No response	478	138	28.9% (24.8-32.9%)	11	2.3% (1.0-3.6%)
<u>Cancer status from NSWCR</u>					
No cancer 1994-2019	37,145	15,592	42.0% (41.5-42.5%)	992	2.7% (2.5-2.8%)
Cancer diagnosed 1994-2019	7,916	3,644	46.0% (44.9-47.1%)	297	3.8% (3.3-4.2%)
>1 cancer	831	415	49.9% (46.5-53.3%)	50	6.0% (4.4-7.6%)
Diagnosed ≤2 years pre-survey	861	477	55.4% (52.1-58.7%)	74	8.6% (6.7-10.5%)
Diagnosed >2 years pre-survey	7,055	3,167	44.9% (43.7-46.1%)	223	3.2% (2.8-3.6%)
<u>Self-reported health conditions</u>					
Cardiovascular disease	9,951	4,943	49.7% (48.7-50.7%)	344	3.5% (3.1-3.8%)
High blood pressure	18,746	8,592	45.8% (45.1-46.5%)	588	3.1% (2.9-3.4%)
Diabetes	4,731	2,189	46.3% (44.8-47.7%)	185	3.9% (3.4-4.5%)

Characteristic	Total number	Out-of-pocket costs >\$1000		Out-of-pocket costs >\$10,000	
		Number	Proportion (95% CI)	Number	Proportion (95% CI)
Blood clot/Thrombosis	2,418	1,182	48.9% (46.9-50.9%)	119	4.9% (4.1-5.8%)
Asthma	6,069	3,006	49.5% (48.3-50.8%)	204	3.4% (2.9-3.8%)
Chronic obstructive pulmonary disease	2,263	1,034	45.7% (43.6-47.7%)	94	4.2% (3.3-5.0%)
Osteoarthritis	10,207	4,806	47.1% (46.1-48.1%)	371	3.6% (3.3-4.0%)
Depression	6,432	3,199	49.7% (48.5-51.0%)	226	3.5% (3.1-4.0%)
Anxiety	5,409	2,652	49.0% (47.7-50.4%)	200	3.7% (3.2-4.2%)
Hay fever	8,772	4,158	47.4% (46.4-48.4%)	268	3.1% (2.7-3.4%)
Lymphoedema	788	378	48.0% (44.5-51.5%)	41	5.2% (3.7-6.8%)
Any of the above	35,136	15,911	45.3% (44.8-45.8%)	1,095	3.1% (2.9-3.3%)
None of the above	9,925	3325	33.5% (32.6-34.4%)	194	2.0% (1.7-2.2%)

CI = confidence interval; NSWCR = New South Wales Cancer Registry.

Table 4. Higher overall out-of-pocket costs by time since cancer diagnosis, among participants diagnosed with cancer

Characteristic	Total number	Out-of-pocket costs >\$1000		Out-of-pocket costs >\$10,000	
		Number	Proportion (95% CI)	Number	Proportion (95% CI)
<u>Time since diagnosis</u>					
>6-12 months	222	138	62.2% (55.8-68.5%)	24	10.8% (6.7-14.9%)
>12-18 months	323	185	57.3% (51.9-62.7%)	32	9.9% (6.6-13.2%)
>18-24 months	316	154	48.7% (43.2-54.2%)	18	5.7% (3.1-8.3%)
>2-3 years	598	274	45.8% (41.8-49.8%)	15	2.5% (1.3-3.8%)
>3-4 years	541	248	45.8% (41.6-50.0%)	19	3.5% (2.0-5.1%)
>4-5 years	514	235	45.7% (41.4-50.0%)	13	2.5% (1.2-3.9%)
>5-6 years	460	216	47.0% (42.4-51.5%)	11	2.4% (1.0-3.8%)
>6-8 years	880	411	46.7% (43.4-50.0%)	32	3.6% (2.4-4.9%)
>8-10 years	791	356	45.0% (41.5-48.5%)	22	2.8% (1.6-3.9%)
>10-15 years	1610	683	42.4% (40.0-44.8%)	60	3.7% (2.8-4.7%)
>15-20 years	1015	455	44.8% (41.8-47.9%)	30	3.0% (1.9-4.0%)
>20 years	646	289	44.7% (40.9-48.6%)	21	3.3% (1.9-4.6%)

Table 5. Associations between participants' demographic and health characteristics and higher out-of-pocket costs (>\$1000, 43% of all participants, and separately, >\$10,000, 3% of participants)*

Characteristic	Total costs >\$1000: adjusted odds ratio (95% CI)	Total costs >\$10,000: adjusted odds ratio (95% CI)
<u>Cancer status</u>		
No cancer	1	1
Cancer 2+ years prior	1.22 (1.15-1.29)	1.10 (0.95-1.29)
Cancer in last 2 years	2.06 (1.77-2.40)	3.30 (2.56-4.26)
<u>Age at follow-up</u>		
<60 years	1	1
60-69	1.13 (1.04-1.22)	1.40 (1.08-1.82)
70-79	1.01 (0.93-1.11)	1.83 (1.38-2.41)
80+	0.88 (0.80-0.98)	1.86 (1.36-2.54)
<u>Sex</u>		
Female	1	1
Male	1.05 (1.01-1.10)	1.12 (0.99-1.27)
<u>Accessibility/Remoteness</u>		
Major cities	1	1
Inner regional	0.99 (0.95-1.04)	0.85 (0.74-0.98)
Outer regional/Remote/Very remote	1.02 (0.95-1.09)	1.10 (0.90-1.36)
<u>Socioeconomic quintile</u>		
Most disadvantaged quintile	1	1
Quintile 2	1.04 (0.97-1.11)	1.05 (0.85-1.30)
Quintile 3	1.08 (1.00-1.16)	1.03 (0.83-1.28)
Quintile 4	1.13 (1.05-1.21)	1.12 (0.90-1.40)
Least disadvantaged	1.43 (1.33-1.54)	1.61 (1.31-1.98)
<u>Household income</u>		
<\$30,000	1	1
\$30,000 - <\$50,000	1.13 (1.06-1.21)	0.95 (0.78-1.17)
\$50,000 - <\$90,000	1.35 (1.26-1.44)	1.23 (1.01-1.49)
\$90,000 - <\$120,000	1.61 (1.47-1.77)	1.36 (1.06-1.75)
\$120,000+	1.62 (1.48-1.76)	1.38 (1.09-1.75)
Unknown/Rather not answer	1.24 (1.15-1.34)	1.27 (1.03-1.57)
<u>Health insurance</u>		
Private	1.64 (1.53-1.75)	1.59 (1.26-2.00)
Dept. of Veterans' Affairs	0.23 (0.18-0.30)	0.32 (0.13-0.79)
Healthcare card	0.80 (0.74-0.88)	0.89 (0.66-1.19)
None	1	1
<u>Highest education</u>		
No school certificate	1	1
School certificate	1.28 (1.15-1.42)	1.12 (0.82-1.53)
High school completed	1.34 (1.19-1.50)	1.02 (0.72-1.44)
Certificate/Diploma/Trade/Apprenticeship	1.35 (1.22-1.49)	1.12 (0.83-1.50)
University+	1.58 (1.42-1.75)	1.12 (0.83-1.52)
<u>Work status</u>		
Paid work/Self-employed	1	1
Retired	0.99 (0.94-1.05)	0.91 (0.78-1.06)
Other (including unemployed, unpaid)	1.09 (1.00-1.19)	1.54 (1.23-1.93)
<u>Marital status</u>		
Married/DeFacto/Partner	1	1
No partner	0.94 (0.90-0.99)	0.94 (0.81-1.08)
<u>Smoking status</u>		

Characteristic	Total costs >\$1000: adjusted odds ratio (95% CI)	Total costs >\$10,000: adjusted odds ratio (95% CI)
Never	1	1
Formerly	1.09 (1.04-1.14)	0.96 (0.85-1.09)
Currently	0.94 (0.82-1.08)	1.08 (0.73-1.58)
<u>Other health conditions</u>		
Cardiovascular disease	1.60 (1.52-1.68)	1.12 (0.98-1.28)
High blood pressure	1.28 (1.23-1.34)	1.08 (0.96-1.21)
Diabetes	1.31 (1.22-1.40)	1.43 (1.21-1.68)
Blood clot/Thrombosis	1.30 (1.18-1.42)	1.60 (1.32-1.96)
Asthma	1.29 (1.21-1.37)	1.11 (0.94-1.31)
Chronic obstructive pulmonary disease	1.20 (1.09-1.32)	1.42 (1.13-1.78)
Osteoarthritis	1.41 (1.34-1.48)	1.39 (1.22-1.59)
Depression	1.36 (1.27-1.45)	1.20 (1.01-1.42)
Anxiety	1.20 (1.12-1.29)	1.28 (1.07-1.53)
Lymphoedema	1.05 (0.90-1.23)	1.40 (1.00-1.97)
Hay fever	1.11 (1.05-1.17)	1.00 (0.86-1.16)

CI = confidence interval.

* See also Box 4 in the main article. All results adjusted for all other listed characteristics.

Table 6. Associations between cancer status and higher out-of-pocket expenses, overall and by cost type and cancer status*

Characteristic	Number	Proportion (95% CI)	Adjusted odds ratio (95% CI)
<u>Total out-of-pocket costs >\$10,000</u>			
No cancer	992	3% (3-3%)	1
Cancer 2+ years prior	223	3% (3-4%)	1.10 (0.95-1.29)
Cancer in last 2 years	74	9% (7-10%)	3.30 (2.56-4.26)
<u>Total out-of-pocket costs >\$1000</u>			
No cancer	15592	42% (41-42%)	1
Cancer 2+ years prior	3167	45% (44-46%)	1.22 (1.15-1.29)
Cancer in last 2 years	477	55% (52-59%)	2.06 (1.77-2.40)
<u>Medications >\$1000</u>			
No cancer	2174	6% (6-6%)	1
Cancer 2+ years prior	527	7% (7-8%)	1.30 (1.17-1.45)
Cancer in last 2 years	79	9% (7-11%)	1.69 (1.32-2.16)
<u>Doctor/Specialist >\$1000</u>			
No cancer	3608	10% (9-10%)	1
Cancer 2+ years prior	886	13% (12-13%)	1.26 (1.16-1.37)
Cancer in last 2 years	227	26% (23-29%)	3.56 (3.02-4.21)
<u>Medical tests >\$1000</u>			
No cancer	621	2% (2-2%)	1
Cancer 2+ years prior	184	3% (2-3%)	1.69 (1.42-2.02)
Cancer in last 2 years	69	8% (6-10%)	5.73 (4.36-7.52)
<u>Hospital/Outpatient >\$1000</u>			
No cancer	1387	4% (4-4%)	1
Cancer 2+ years prior	290	4% (4-5%)	1.07 (0.93-1.22)
Cancer in last 2 years	120	14% (12-16%)	4.22 (3.42-5.21)
<u>Dental care >\$1000</u>			
No cancer	3847	10% (10-11%)	1
Cancer 2+ years prior	702	10% (9-11%)	1.02 (0.93-1.11)
Cancer in last 2 years	80	9% (7-11%)	0.96 (0.76-1.22)
<u>Allied health >\$1000</u>			
No cancer	581	2% (1-2%)	1
Cancer 2+ years prior	91	1% (1-2%)	0.91 (0.73-1.15)
Cancer in last 2 years	15	2% (1-3%)	1.35 (0.80-2.28)
<u>Other complementary/ alternative >\$1000</u>			
No cancer	325	1% (1-1%)	1
Cancer 2+ years prior	42	1% (0-1%)	0.84 (0.60-1.18)
Cancer in last 2 years	6	1% (0-1%)	1.04 (0.46-2.36)
<u>Medical equipment >\$1000</u>			
No cancer	226	1% (1-1%)	1
Cancer 2+ years prior	NR	1% (1-1%)	1.03 (0.75-1.42)
Cancer in last 2 years	NR	<1% (<1-<1%)	0.64 (0.24-1.75)
<u>Practical/travel >\$1000</u>			
No cancer	283	1% (1-1%)	1
Cancer 2+ years prior	62	1% (1-1%)	1.15 (0.86-1.53)
Cancer in last 2 years	18	2% (1-3%)	2.78 (1.69-4.56)
<u>Home/other modifications >\$1000</u>			
No cancer	235	1% (1-1%)	1
Cancer 2+ years prior	52	1% (1-1%)	0.95 (0.70-1.30)
Cancer in last 2 years	7	1% (0-1%)	1.10 (0.51-2.37)

Characteristic	Number	Proportion (95% CI)	Adjusted odds ratio (95% CI)
<u>Other healthcare >\$1000</u>			
No cancer	352	1% (1-1%)	1
Cancer 2+ years prior	88	1% (1-2%)	1.20 (0.94-1.53)
Cancer in last 2 years	15	2% (1-3%)	1.92 (1.13-3.27)

CI = confidence interval; NR = not reported because cell count or related cell count is lower than 5.

* See also Box 5 in the main article. All results adjusted for age at follow-up, sex, remoteness, socioeconomic quintile, household income, health insurance status, education, work status, marital status, smoking status, and other health conditions.

Table 7. Out-of-pocket expenses for people with total out-of-pocket expenses exceeding \$1000, by cost type and cancer status*

Characteristic	Number	Proportion
<u>Medications >\$1000</u>		
No cancer	1951	13%
Cancer 2+ years prior	464	15%
Cancer in last 2 years	75	16%
<u>Doctor/Specialist >\$1000</u>		
No cancer	3340	21%
Cancer 2+ years prior	818	26%
Cancer in last 2 years	211	44%
<u>Medical tests >\$1000</u>		
No cancer	565	4%
Cancer 2+ years prior	170	5%
Cancer in last 2 years	67	14%
<u>Hospital/Outpatient >\$1000</u>		
No cancer	1286	8%
Cancer 2+ years prior	271	9%
Cancer in last 2 years	114	24%
<u>Dental care >\$1000</u>		
No cancer	3553	23%
Cancer 2+ years prior	644	20%
Cancer in last 2 years	74	16%

* No cancer: 15,592 people; cancer diagnosed more than two years before survey: 3167 people; cancer diagnosed during two years preceding survey: 477 people.

Not shown because of small cell counts: allied health care, other complementary/alternative treatments, medical equipment, practical/travel, home/other modifications, any other health care costs.

Table 8. Associations between cancer type, time since diagnosis and higher out-of-pocket costs

Cancer type and timing	n	Total costs >\$1000			Total costs >\$10,000		
		Number	Proportion (95% CI)	Adjusted odds ratio (95% CI)	Number	Proportion (95% CI)	Adjusted odds ratio (95% CI)
No cancer	37,145	15,592	42% (41-42%)	1	992	(3%, 3-3%)	1
Breast cancer >2 years	1471	643	44% (41-46%)	1.15 (1.02-1.29)	40	3% (2-4%)	0.90 (0.64-1.26)
Colorectal cancer >2 years	728	289	40% (36-43%)	1.09 (0.92-1.28)	17	2% (1-3%)	0.84 (0.51-1.37)
Melanoma >2 years	1231	569	46% (43-49%)	1.27 (1.12-1.43)	48	4% (3-5%)	1.41 (1.05-1.91)
Prostate cancer >2 years	1967	917	47% (44-49%)	1.23 (1.11-1.37)	73	4% (3-5%)	1.27 (0.98-1.64)
Other cancer >2 years	1658	749	45% (43-48%)	1.28 (1.15-1.43)	45	3% (2-3%)	0.98 (0.72-1.34)
Breast cancer ≤2 years	139	75	54% (46-62%)	1.90 (1.32-2.75)	9	6% (2-11%)	2.53 (1.26-5.05)
Colorectal cancer ≤2 years	91	47	52% (41-62%)	2.40 (1.46-3.94)	NR	<5% (NR)	1.76 (0.63-4.88)
Melanoma ≤2 years	134	72	54% (45-62%)	1.70 (1.17-2.48)	NR	<5% (NR)	1.23 (0.50-3.06)
Prostate cancer ≤2 years	203	134	66% (59-73%)	3.09 (2.23-4.30)	37	18% (13-24%)	7.80 (5.33-11.41)
Other cancer ≤2 years	294	149	51% (45-56%)	1.72 (1.33-2.22)	19	6% (4-9%)	2.45 (1.52-3.96)

CI = confidence interval; NR = not reported because cell count or related cell count is lower than 5.

* See also Box 7 in the main article. Adjusted for age at follow-up, sex, remoteness, socioeconomic quintile, household income, health insurance status, education, work status, marital status, smoking status, and other health conditions.

Table 9. Associations between detailed cancer status, participants' characteristics and higher out-of-pocket costs, among people with cancer

	n	Total costs >\$1000			Total costs >\$10,000		
		Number	Proportion (95% CI)	Adjusted odds ratio (95% CI)	Number	Proportion (95% CI)	Adjusted odds ratio (95% CI)
<u>Multiple cancers</u>							
No	7085	3229	46% (44-47%)	1	247	(3%, 3-4%)	1
Yes	831	415	50% (47-53%)	1.28 (1.09-1.52)	50	6% (4-8%)	1.74 (1.24-2.45)
<u>Cancer stage at diagnosis</u>							
Localised	4646	2140	46% (45-47%)	1	172	4% (3-4%)	1
Non-localised	1698	788	46% (44-49%)	1.08 (0.95-1.23)	68	4% (3-5%)	1.19 (0.87-1.63)
Unknown	1572	716	46% (43-48%)	1.03 (0.90-1.19)	57	4% (3-5%)	0.93 (0.66-1.31)
<u>Age at diagnosis</u>							
<60 years	2577	1289	50% (48-52%)	1	89	3% (3-4%)	1
60-69	2952	1396	47% (45-49%)	0.97 (0.86-1.09)	103	3% (3-4%)	0.87 (0.63-1.20)
70-79	1904	778	41% (39-43%)	0.79 (0.68-0.92)	82	4% (3-5%)	1.03 (0.71-1.48)
80+	483	181	37% (33-42%)	0.75 (0.59-0.96)	23	5% (3-7%)	1.14 (0.65-1.99)

CI = confidence interval

Adjusted for cancer type, diagnosis ≤ 2 years or > 2 years, sex, remoteness of residence, socioeconomic quintile, household income, health insurance status, education, work status, marital status, smoking status, and other health conditions.

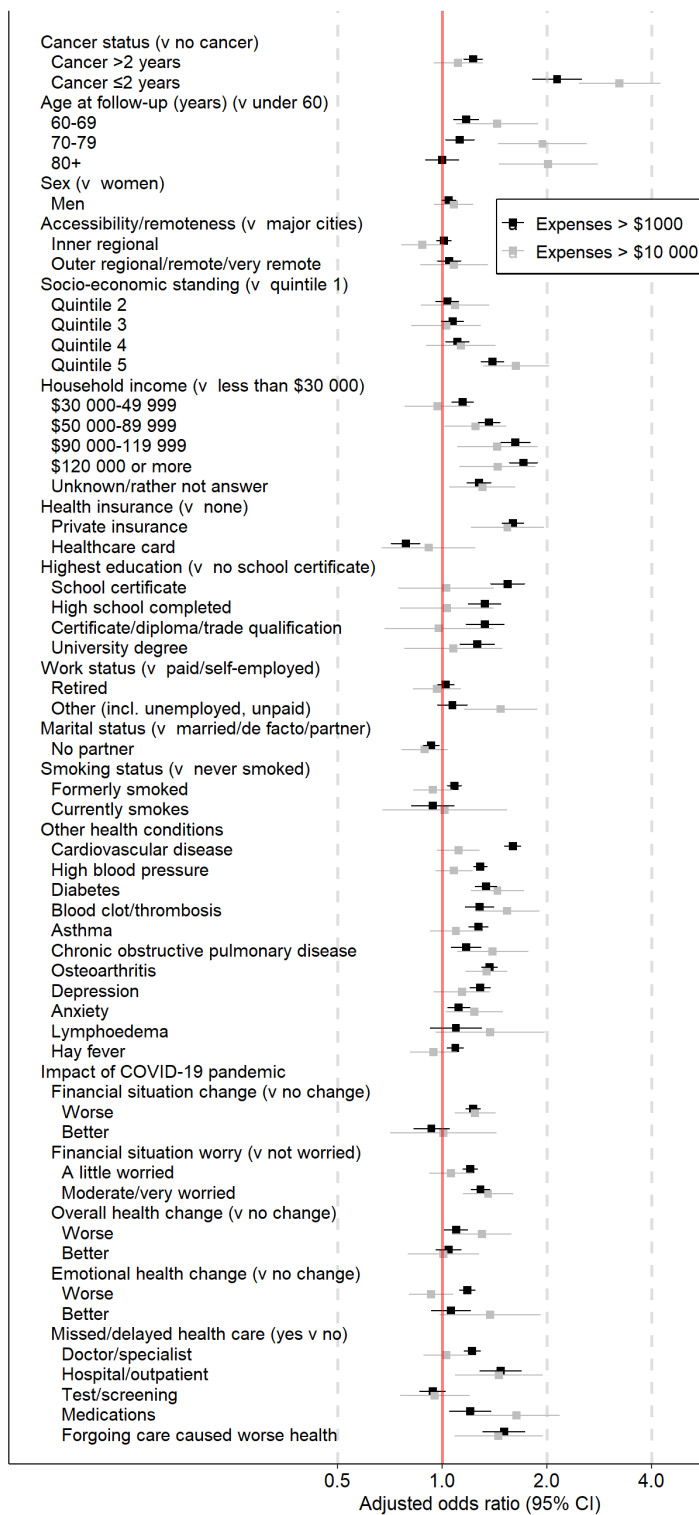
Table 10. Impact of COVID-19 pandemic on 45 and Up Study follow-up survey respondents (2020), overall and by cancer status

Characteristic	All people		People with cancer		People with no cancer	
	All people	Proportion	People with cancer	Proportion	People with no cancer	Proportion
All respondents	45,061		7,916		37,145	
<u>Financial situation change</u>						
Worse	12,577	28%	2,108	27%	10,469	28%
No change	30,414	67%	5,459	69%	24,955	67%
Better	1,512	3%	252	3%	1,260	3%
Missing	558	1%	97	1%	461	1%
<u>Financial situation worry</u>						
Not worried	22,518	50%	4,188	53%	18,330	49%
A little worried	12,940	29%	2,183	28%	10,757	29%
Moderate/very worried	9,194	20%	1,460	18%	7,734	21%
Missing	409	1%	85	1%	324	1%
<u>Overall health change</u>						
Worse	4,112	9%	660	8%	3,452	9%
No change	36,650	81%	6,579	83%	30,071	81%
Better	3,764	8%	571	7%	3,193	9%
Missing	535	1%	106	1%	429	1%
<u>Emotional health change</u>						
Worse	11,763	26%	1,829	23%	9,934	27%
No change	31,043	69%	5,684	72%	25,359	68%
Better	1,599	4%	275	3%	1,324	4%
Missing	656	1%	128	2%	528	1%
<u>Missed/delayed health care</u>						
Doctor	10,159	23%	1,688	21%	8,471	23%
Hospital	1,217	3%	243	3%	974	3%
Test/screening	3,467	8%	528	7%	2,939	8%
Medicine	1,273	3%	227	3%	1,046	3%
Any of the above	11,823	26%	1,961	25%	9,862	27%
<i>This caused worse health</i>	1,280	3%	206	3%	1,074	3%

For most outcomes, there was an association between high out-of-pocket costs and at least one of these COVID-19 questions, most frequently worry about financial situation because of COVID-19, and often overlap between the question and the outcome. For example, missing/delaying hospital care because of COVID-19 was associated with high hospital/outpatient out-of-pocket costs, and missing/delaying medications because of COVID-19 was associated with high medication out-of-pocket costs. However, the inclusion of the COVID-19-related questions generally made little difference to the association between cancer status and the outcomes of interest reported in the main results (compare Box 4 with figures 2a and 2b below), and for the sake of parsimony, these regression results were not reported.

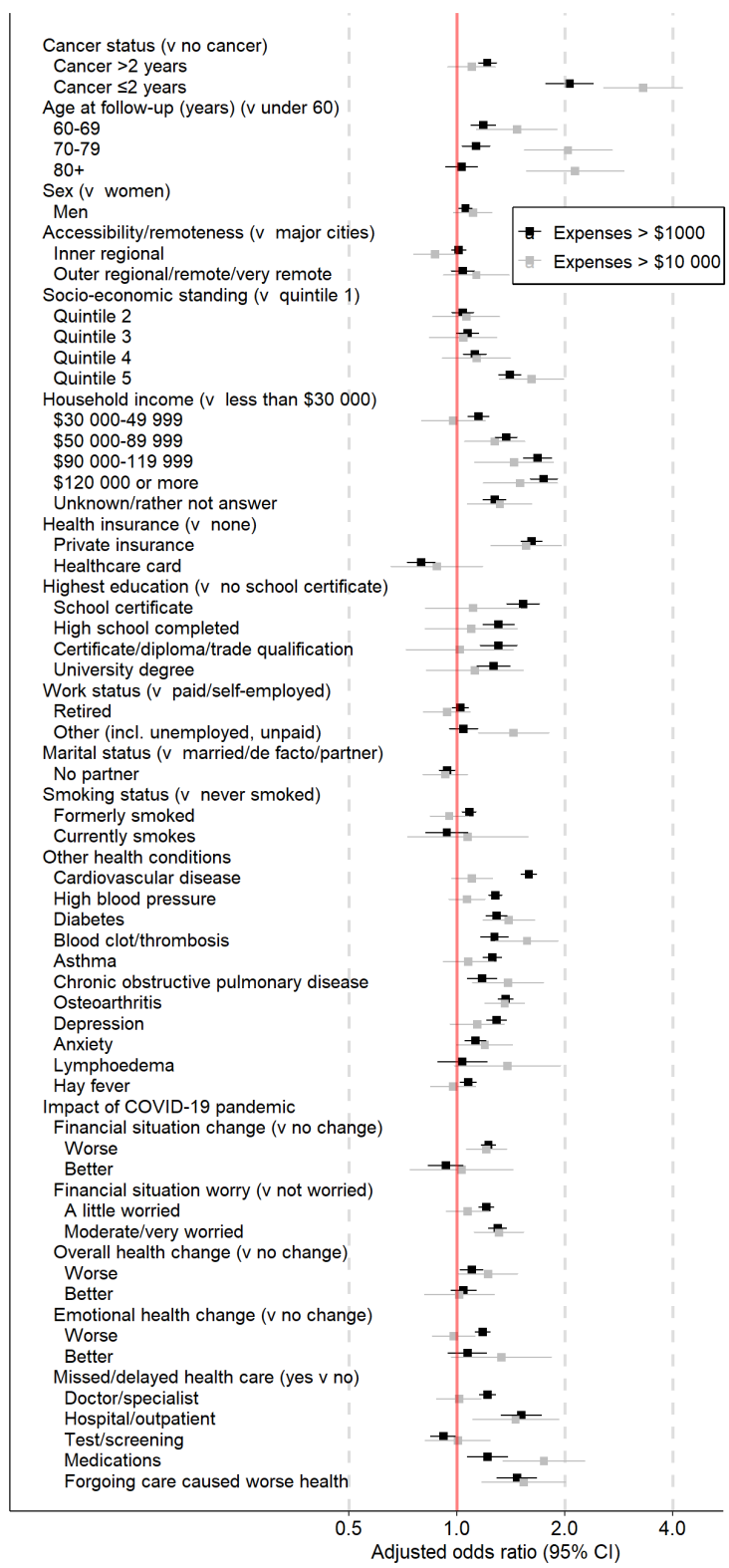
The costing period in our analysis related to the 12 months prior to the questionnaire. As the questionnaires were sent out during July-December 2020, this meant the study period included the first months of the COVID-19 pandemic. At the time of the survey, NSW had emerged from a 2-month lockdown in March-May 2020 (timing and duration depending on the region), with very few COVID-19 cases relative to the rest of the world [1,2]. Financial stability would have been affected by the pandemic for many people, with implications for health service use, as found in our study and elsewhere [3]. For people with cancer, the health care problems caused by pandemic-related lockdowns and restrictions on non-essential treatment, for example, may have affected the initial treatment phase less than those in their second or subsequent years of follow-up, and overall it may have had less impact than for other health conditions.

Figure 2a. Out-of-pocket health care costs >\$1000 (43% of all participants) and >\$10,000 (3%), by demographic and health characteristics and COVID-19 pandemic effects



All results adjusted for all other characteristics. Department of Veterans' Affairs (health insurance) results (not shown because of visual skew of graph): adjusted odds ratios (v no insurance), 0.23 (95% CI, 0.18–0.30) for >\$1,000 and 0.38 (95% CI, 0.15–0.94) for >\$10,000.

Figure 2b. Out-of-pocket health care costs >\$1000 and >\$10,000, by demographic and health characteristics and COVID-19 pandemic effects health characteristics - sensitivity analysis setting missing COVID-related questions to “no change”/“no”



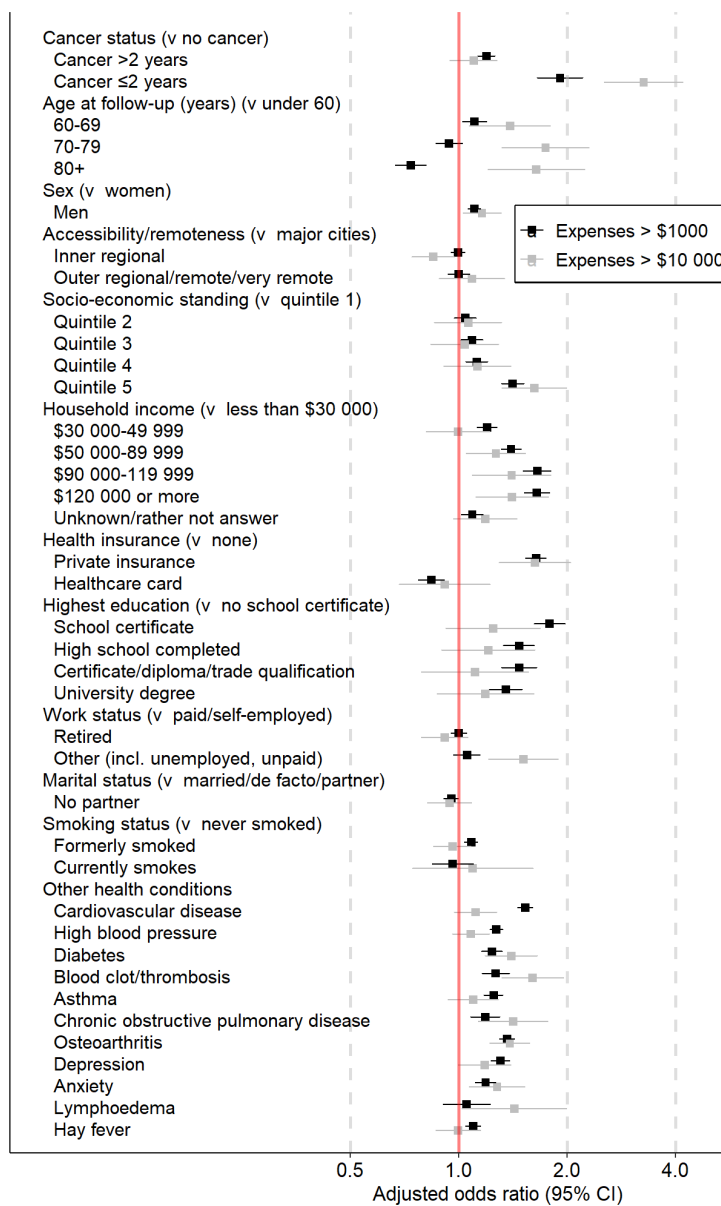
All results adjusted for all other characteristics. Department of Veterans’ Affairs (health insurance) results (not shown because of visual skew of graph): adjusted odds ratios (v no insurance), 0.24 (95% CI, 0.18–0.30) for >\$1,000 and 0.33 (95% CI, 0.13–0.82) for >\$10,000.

Other sensitivity analyses

For all out-of-pocket cost outcomes of interest, there were similar results to the all-participant results when restricting to people without cancer (Figure 3), as well as when setting unsure/missing responses to the “No” option for COVID 19-related questions (Figure 2b). We tested setting missing overall costs to low/high values and in all scenarios there were only minor changes to the effect estimates for cancer status (Figures 4 and 5). The one exception was setting all missing values to >\$10,000: the aOR for cancer < 2 years vs no cancer changed from 3.30 (2.56-4.26) to 1.98 (1.62-2.42), but this is based on an unrealistic assumption of extreme high costs (the same assumption changed the aOR for >\$1000 from 2.06 to 1.94) (Figure 5). The sensitivity test using the count of other health conditions instead of the 11 individual conditions found that the count was strongly associated with higher out-of-pocket costs, but the change made little difference to the effect estimates for cancer status (Figure 6).

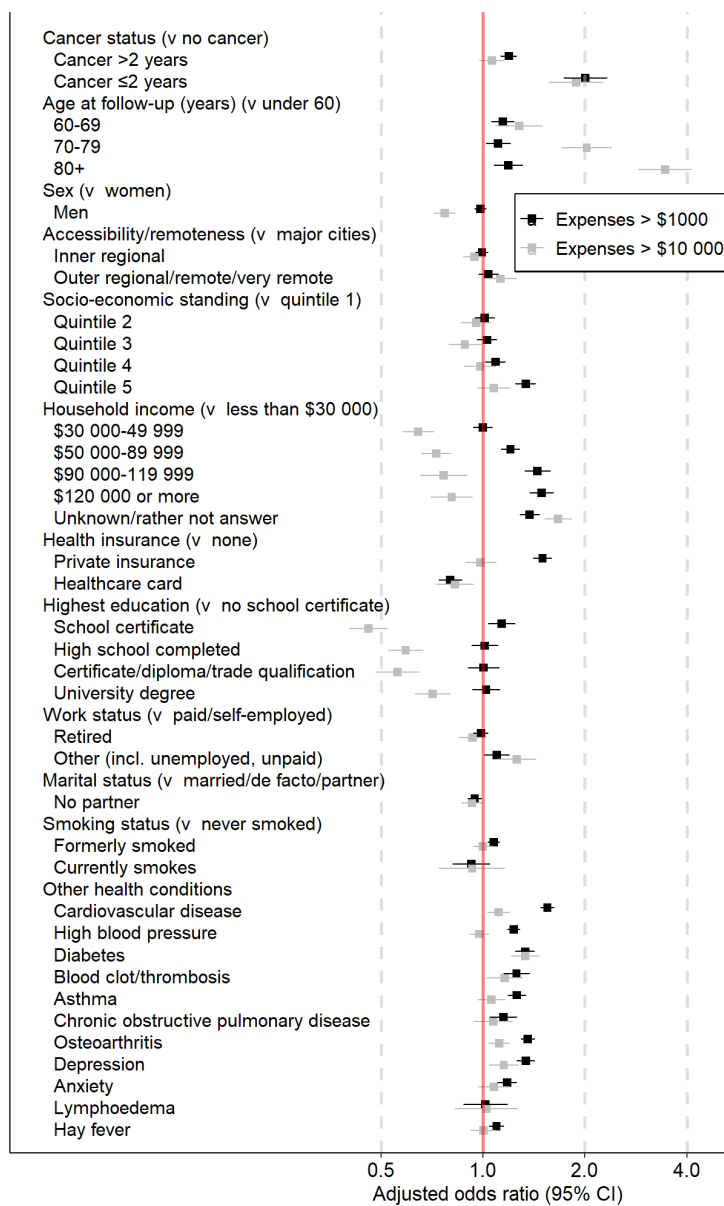
As noted in the main article, based on the cost categories in the questionnaire, we chose to focus on costs >\$1000. We also analysed costs >\$250 for the less common cost types, but generally found few differences in effect size/direction compared to analyses of costs >\$1000. Given the costs at the lower end equate to a relatively low \$5 per week, we did not include these results, still acknowledging that for some people, even \$250 as a lump sum can be very difficult to access.

Figure 3. Out-of-pocket health care costs >\$1000 and >\$10,000, by demographic and health characteristics - sensitivity analysis setting missing/unknown costs to ≤\$1000 and ≤\$10,000



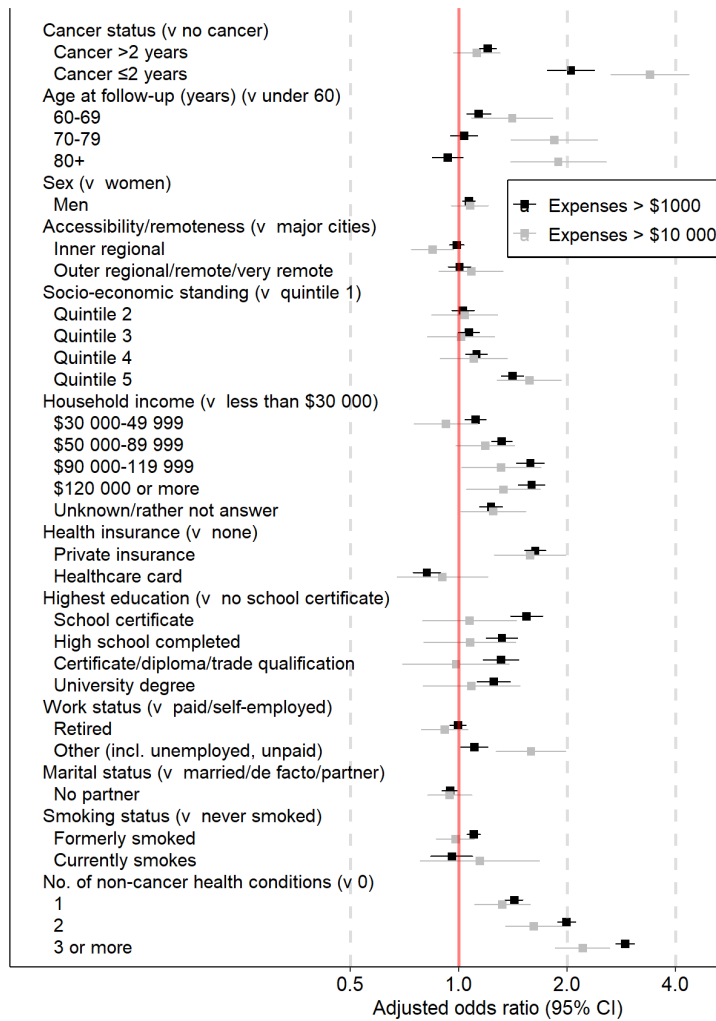
All results adjusted for all other characteristics. Department of Veterans' Affairs (health insurance) results (not shown because of visual skew of graph): adjusted odds ratios (v no insurance), 0.25 (95% CI, 0.20–0.32) for >\$1,000 and 0.33 (95% CI, 0.13–0.81) for >\$10,000.

Figure 4. Out-of-pocket health care costs >\$1000 and >\$10,000, by demographic and health characteristics: sensitivity analysis setting missing/unknown costs to >\$1000 and >\$10,000



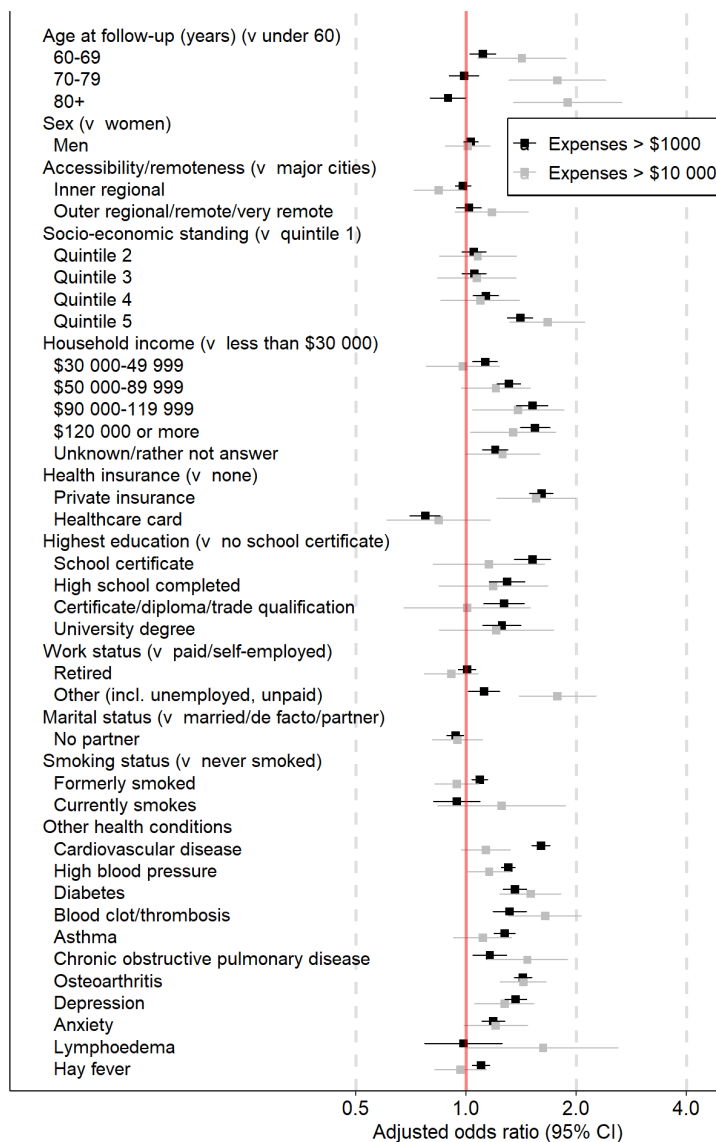
All results adjusted for all other characteristics. Department of Veterans' Affairs (health insurance) results (not shown because of visual skew of graph): adjusted odds ratios (v no insurance), 0.32 (95% CI, 0.26–0.39) for >\$1,000 and 0.73 (95% CI, 0.56–0.96) for >\$10,000. Note: The sensitivity analysis setting all missing values to have costs >\$10,000 is based on a somewhat implausible assumption that substantially increases the odds of high costs for people with the lowest household income and education levels.

Figure 5. Out-of-pocket health care costs >\$1000 and >\$10,000, by demographic and health characteristics: sensitivity analysis using number of non-cancer health conditions



All results adjusted for all other characteristics. Department of Veterans' Affairs (health insurance) results (not shown because of visual skew of graph): adjusted odds ratios (v no insurance), 0.25 (95% CI, 0.19–0.32) for >\$1,000 and 0.34 (95% CI, 0.14–0.85) for >\$10,000.

Figure 6. Out-of-pocket health care costs >\$1000 and >\$10,000, by demographic and health characteristics: sensitivity analysis excluding participants with cancer diagnoses



All results adjusted for all other characteristics. Department of Veterans' Affairs (health insurance) results (not shown because of visual skew of graph): adjusted odds ratios (v no insurance), 0.23 (95% CI, 0.17–0.30) for >\$1,000 and 0.43 (95% CI, 0.17–1.07) for >\$10,000.

References

1. Storen R, Corrigan N. COVID-19: a chronology of state and territory government announcements [report]. Canberra: Parliament of Australia. (Research paper series, 2020-21.) https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp2021/Chronologies/COVID-19StateTerritoryGovernmentAnnouncements (viewed June 2023).
2. World Health Organization. WHO Coronavirus (COVID-19) dashboard. <https://covid19.who.int/region/wpro/country/au> (viewed June 2023).
3. Dawson G, Bleicher K, Baynes S, et al. 45 and Up COVID Insights: a dynamic and collaborative approach to evidence-making during the COVID-19 pandemic. *Public Health Res Pract* 2022; 32: e32232214.

STROBE statement: checklist of items that should be included in reports of cross-sectional studies

	Item No.	Recommendation	Comments*
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	In abstract.
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Done.
Introduction			
Background/ rationale	2	Explain the scientific background and rationale for the investigation being reported	Introduction (paragraphs 1-3).
Objectives	3	State specific objectives, including any prespecified hypotheses	Introduction (paragraph 3).
Methods			
Study design	4	Present key elements of study design early in the paper	Methods (Data sources).
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Methods (Data sources), Results (paragraph 1), Supporting Information (Figure 1).
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	Methods (Data sources), Supporting Information (Fig. 1).
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Methods (Costs, Participant characteristics).
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Methods (Costs, Participant characteristics).
Bias	9	Describe any efforts to address potential sources of bias	Methods (Statistical methods); Results (paragraphs 3-5).
Study size	10	Explain how the study size was arrived at	Methods (Data sources), Supporting Information (Fig. 1).
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Methods (Costs; Statistical methods)
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Methods (Statistical methods); Results (paragraphs 3-5).
		(b) Describe any methods used to examine subgroups and interactions	Methods (Statistical methods); Results (parag. 4-5); Supporting Information (Other analyses).
		(c) Explain how missing data were addressed	Methods (Statistical methods); Results (paragraphs 3-5).
		(d) If applicable, describe analytical methods taking account of sampling strategy	Methods (Statistical methods).
		(e) Describe any sensitivity analyses	Methods (Statistical methods); Results (paragraphs 3-4); Supporting Information (Other analyses).
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Methods (Data sources), Results (paragraph 1), Supporting Information (Figure 1).
		(b) Give reasons for non-participation at each stage	Supporting Information (Fig. 1).
		(c) Consider use of a flow diagram	Supporting Information (Fig. 1).
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Results (paragraph 1); Tables 1-2.
		(b) Indicate number of participants with missing data for each variable of interest	Tables 1-2.
Outcome data	15*	Report numbers of outcome events or summary measures	Results (paragraphs 1-2); Tables 1-2
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Multiple tables and figures in the main text and Supporting Information.
		(b) Report category boundaries when continuous variables were categorized	Methods (Costs); Tables 1-2.
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Methods (Statistical methods); Results (paragraphs 3-4); Supporting Information (Other analyses).
Discussion			
Key results	18	Summarise key results with reference to study objectives	Discussion (paragraphs 1-6).
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Discussion (paragraphs 7-8).
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Throughout the Discussion.
Generalisability	21	Discuss the generalisability (external validity) of the study results	Throughout the Discussion.
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Part of submission process.

* Paragraph/figure/table numbers relate to the original submitted manuscript and do not apply to the published version of the article or its Supporting Information.