

## Full Paper

## The health and well-being of cancer survivors in the UK: findings from a population-based survey

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**BACKGROUND:** To compare self-reported health and well-being in a sample of cancer survivors with individuals who have not had cancer and with individuals who have a serious chronic condition other than cancer.

**PATIENTS AND METHODS:** A cross-sectional survey drawn from an online panel of 400 000 UK citizens supplemented with other online recruitment and telephone recruitment. The participants were 4892 individuals 30 years of age or above, including 780 individuals with a previous cancer diagnosis, 1372 individuals with one or more of 10 chronic conditions but not cancer and 2740 individuals without a previous cancer diagnosis or chronic condition. Thirteen measures of health and well-being were constructed from answers to 25 survey items covering physical, psychological and social dimensions of health and well-being.

**RESULTS:** Cancer survivors were significantly more likely to report poor health outcomes across all 13 measures than those with no history of cancer or a chronic condition. The adjusted odds ratios for cancer survivors with no chronic conditions compared with healthy participants ranged from 1.37 (95% confidence interval (CI): 1.31–1.96) for emotional well-being to 3.34 (95% CI: 2.74–4.08) for number of health professionals consulted in the last 12 months. The health profile of cancer survivors was similar to those with a history of a serious chronic health condition.

**CONCLUSIONS:** A substantial number of individuals who have had a diagnosis of cancer experience ongoing poor health and well-being following cancer and cancer treatment. The results of this study provide an initial basis for the development of specific help and support for cancer survivors.

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As in the US and Europe, survival for cancer in the UK has been improving steadily over the last 30 years, with average survival at 10 years being 46.2% compared with 23.6% 30 years ago, and the 5-year survival rate now approaching 50% of all patients (Cancer Research UK, 2007). Improvements in cancer survival rates for UK citizens are reflected across European countries and internationally for cancers of the colon, rectum, breast and prostate, as well as some of the less common cancers (Department of Health, 2009, 2010). Although there may be a debate about whether the rate of improvement in the UK is fast enough relative to the best in Europe, or whether they indicate more effective cancer services, these figures indicate considerable improvement in cancer management (Berrino *et al*, 2009; Brenner *et al*, 2009; Francisci *et al*, 2009). However, the good news of improving cancer survival statistics masks what is now a longer disease trajectory with increasingly unpredictable health outcomes for individuals and where little is known about the

long-term implications for life following cancer, and this has led to the call for greater focus to be placed on cancer survivors (Aziz and Rowland, 2003; Ganz, 2005; Hewitt *et al*, 2005; Earle, 2007; Corner, 2008). Developing an understanding of the problems people face following primary cancer treatment and how the health system should respond to these problems is therefore an important agenda recently recognised with the launch of the National Cancer Survivorship Initiative for England (Department of Health, 2010).

There are approximately 2 million cancer survivors in the UK today, a figure only recently calculated as one of a number of activities for the National Cancer Survivorship Initiative for England. In those aged 65 years and above, more than 13% of the population are cancer survivors (Maddams *et al*, 2009). In the coming years, this number will continue to increase as a result of the growing and ageing population of the UK, increased detection of cancer and improving survival. The annual rate of increase in the number of cancer survivors is estimated to be currently around 3%, and it is anticipated that this rate of increase will continue into the future (Maddams *et al*, 2009).

Long-term health and well-being following cancer treatment has not until recently been the focus of the UK health policy, or for cancer services or research. Although there have been considerable

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Some preliminary results of the study are presented in National Cancer Survivorship Initiative Vision, Department for Health, London, UK, January 2010.

studies of quality of life among individuals undergoing cancer treatment, some of which have assessed the long-term impact of a cancer diagnosis on quality of life, few studies have systematically studied the health outcomes of people treated for cancer over the years following initial treatment. Although there is a growing international literature on cancer survivorship, there are no published studies that have been undertaken among UK cancer survivors beyond the first months following treatment and just a few internationally, and there are few population-based studies or studies comparing cancer survivors with individuals with other conditions (Schultz *et al*, 2003; Yarbrough *et al*, 2004; Nord *et al*, 2005; Mandelblatt *et al*, 2006; Armes *et al*, 2009; Jansen *et al*, 2010). For those studies that have been undertaken, sampling methods, sample sizes and a lack of robust or defined measures to assess the long-term health consequences of cancer make it difficult to draw firm conclusions from the data. The National Health Interview Study in the United States has been used as a source of data for examining health and disability among cancer survivors. Analysing data from this study, Hewitt and Rowland (2002) and Hewitt *et al* (2003) found that individuals with a cancer history responding to the survey were significantly more likely to report poor health and to have other chronic conditions and limitations to their ability to carry out usual activities.

One aim of the study reported here was to use a similar approach to the analysis of data from the National Health Interview Study, but with UK citizens, comparing health outcomes of cancer survivors with a sample of the UK population who have not had cancer or any other serious chronic condition. A second aim was to compare cancer survivors with people with other chronic diseases. The study set out to test the hypothesis that cancer survivors in the UK have poorer health than individuals who have not had treatment for cancer.

The overall purpose of the study was to inform development of health policy in the UK, in particular the England Department of Health National Cancer Survivorship Initiative. It was also intended to inform future research relating to the long-term health outcomes for cancer survivors, to identify possible measures of long-term health and health system actions that might be taken to address problems or issues identified. Data were collected in 2008 and our initial descriptive analysis of data from the study was reported in the National Cancer survivorship Initiative Vision Document (Department of Health, 2010). The findings reported here are the results of a secondary and more detailed analysis of data from the study. It is the first major study of the UK population assessing the health outcomes of cancer survivors.

## MATERIALS AND METHODS

To explore the self-reported health and well-being of recent and long-term cancer survivors, a population-based survey approach was adopted for the study. Identifying a sample for the study presented a number of methodological challenges. Cancer registries, although being the standard source of data on individuals who have had cancer, could not provide an equivalent sample of individuals without a cancer diagnosis. In the UK, there is no equivalent survey to the National Health Interview Study conducted by the US National Centre for Health Statistics, which is similar to the UK census but uses a telephone survey approach to ask questions focussed around health (National Centre for Health Statistics, 2002; Pleis and Lethbridge-Cejku, 2006). Instead, the principal recruitment method adopted for our study was a survey with members of an online panel provided by the market research online fieldwork and panel specialist company Research Now, London, UK, which had over 400 000 members aged 18 years and above from a cross-section of demographic groups throughout the UK. The recruitment through

the online panel was supplemented with telephone recruitment using random selection from general telephone lists and supplementary online recruitment to ensure participation by harder-to-reach groups who may not have access to computers, for example, older people. The study used a market research approach, and thus local research ethics committee approval was not required. The study instead followed the UK Market Research Society guidelines ([www.mrs.org.uk/standards/codeconduct.htm](http://www.mrs.org.uk/standards/codeconduct.htm)) and the ethical framework from the Macmillan Cancer Support, a UK-based cancer charity.

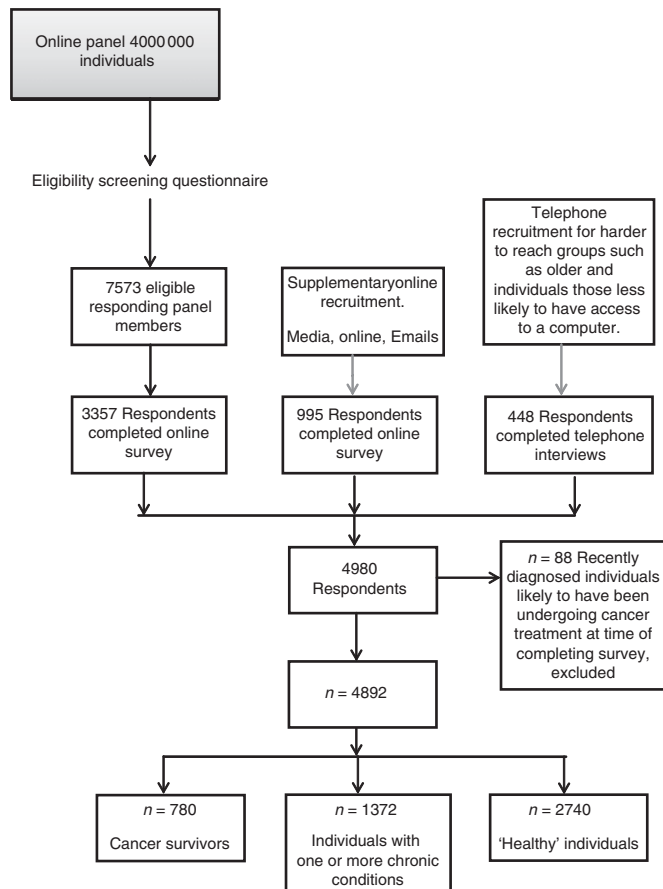
## Sample

Recruitment was limited to those above 30 years of age. For cancer survivors, the eligible cancer types were as follows: a self-reported diagnosis of breast, prostate, gynaecological, bowel and 'other' excluding lung, skin and (upper) gastrointestinal cancers to exclude individuals who had cancers with very poor survival rates (lung and upper gastrointestinal cancer) or cancers in which there is minimal treatment required and have few, if any, consequences (skin). For the other chronic conditions, those eligible were people who self-reported that they had ever been diagnosed with diabetes (other than solely during pregnancy); a stroke; any heart condition (coronary heart disease, angina, myocardial infarction or other heart condition); emphysema, arthritis, rheumatoid arthritis, lupus, gout or fibromyalgia; osteoporosis; and those who self-reported that they had been diagnosed in the last 12 months with any of the following: asthma; stomach, duodenal or peptic ulcer; weak or failing kidneys, excluding kidney stones; and any liver condition. Healthy participants were those aged above 30 years who had not been diagnosed with cancer or one of the chronic conditions listed.

A random selection of panel members were invited to complete a short screening questionnaire to collect basic demographic information and to identify whether they had been diagnosed with cancer and/or other specified chronic conditions, and for those with cancer the year of diagnosis and type. Sample quotas were set to ensure that there were sufficient participants of each of the groups of interest: cancer survivors, including recent and longer-term survivors and each of the specified cancer types, and people with each of the specified chronic conditions. Those who responded, who were eligible and needed to fill a quota, were then sent a link to the main online questionnaire. They were paid a small incentive of £2 on completion of the questionnaire in accordance with the terms of membership of the online panel. Evidence from a recent Cochrane review suggests that this is an effective method of increasing sample response rates in large-scale surveys (Edwards *et al*, 2009).

All of the total of 7573 panel members who responded to a screening questionnaire indicating that they were eligible were invited to participate in the study. Of these, 3357 panel members completed the online survey, with a response rate of 47%. A further 1443 individuals completed the questionnaire through the supplementary online recruitment approaches (995 participants) and telephone recruitment (448 participants; see Figure 1). The random sample of participants who were interviewed by telephone were cold-called and, if willing to participate, they were asked the screening questions, followed by the main questions if eligible. The two methods of data collection were compared to confirm that they provided equivalent results in relation to responses to questionnaire items.

To check the representativeness of the sample, the distribution by age, UK nation and sex in the sample were compared with figures for the UK population taken from the Office for National Statistics mid-2005 population estimates. Apart from sex, where men were underrepresented in the survey, these distributions were very similar. However, as noted below, sex, nation and age were controlled for in the regression models.



**Figure 1** Flow diagram of study recruitment.

### Study measures

As at the time of data collection there was no consensus over the most appropriate measures of health outcome for long-term cancer survivors, health and well-being was assessed using 25 items from the National Health Interview Study (Hewitt and Rowland, 2002; Hewitt *et al*, 2003) adapted for the UK, where there were differences for language and terminology and incorporating two additional items from the Quality of Life after Cancer Scale (Avis *et al*, 2006) and two items on financial problems and debt. The questionnaire was piloted before use in the main survey.

For the analysis, 13 measures of health outcomes were constructed from the 25 items in the survey. These were as follows:

1. General health.
2. Difficulty participating in vigorous activities.
3. Physical well-being, constructed by categorising the mean score of responses on a five-point scale to five questions on the ability to carry out various activities, such as personal-care tasks, housework, social activities, going out to do things and doing things with children.
4. A measure of whether aches and pains were a problem.
5. A continuous measure of psychological well-being based on the mean score of responses on a five-point scale to three questions concerning the following: (1) having a positive outlook on life; (2) having lots of energy; and (3) being satisfied with life.
6. A measure of emotional well-being, constructed by categorising the single-factor score from a factor analysis of the responses on a five-point scale to six questions concerning the following: (1) feeling anxious; (2) being affected by mood swings; (3) worrying about dying; (4) feeling depressed; (5)

feeling nervous and on-edge; and (6) feeling that there was no reason to be alive.

7. A measure of cognitive well-being constructed by categorising the mean score of responses on a five-point scale to two questions concerning the following: (1) having difficulty doing things that require concentration; and (2) having trouble remembering.
8. The extent to which health has prevented the participant from working in their preferred occupation.
9. Number of different health professionals consulted in the last 12 months.
10. Number of different health services used in the last 12 months.
11. Number of times the participant had seen a doctor or other health-care professional about their own health in a doctor's surgery, walk-in clinic or outpatient clinic in the last 12 months.
12. Problems paying for everyday items.
13. Problems with debt.

### Statistical analysis

The measures of health outcomes were compared by participant group, controlling for a number of background variables. There were five groups of participants:

1. Cancer survivors with no chronic conditions
2. Cancer survivors with at least one chronic condition
3. Participants with one chronic condition
4. Participants with two or more chronic conditions
5. Participants who did not report a diagnosis of cancer or another chronic condition and were therefore described as 'healthy'.

Six variables were controlled for: nation, sex, age, household structure, carer status (primary, occasional or not a carer) and method of interview (online or telephone). Method of interview was included to control for any differences in responses depending on how the data were collected.

Before modelling, bivariate analysis of the relationships between the participant group and the outcome measures was undertaken. Regression modelling of each outcome measure individually was undertaken. The explanatory variables were the six background variables and participant group. Table 1 presents the distribution of individuals in the categories of these six background variables, and Table 2 presents the distribution of the individuals for the measures of health and well-being, both overall and by participant group.

$\chi^2$ -Tests were used to test for differences between the groups, except for psychological well-being where a one-way ANOVA test was performed. Regression modelling of each outcome measure individually was undertaken. The explanatory variables were the six background variables and participant group. For all but three of the outcome measures, ordinal logistic regression models were used. As stated by McCormack *et al* (2003), these models assume that the effect of each explanatory variable on any dichotomy of the ordinal outcome is constant and can be summarised by a common odds ratio, and this approach has also been used by Fallowfield *et al* (2010). A linear regression model was used for the continuous measure of psychological well-being, a binary logistic regression model for the aches and pains measure and a multinomial logistic regression model for problems with debt. The variables defined in measures 9–11 above were treated as ordinal with categories given in Table 2, rather than counts. The initial descriptive analysis performed for the National Cancer Survivorship Initiative (Department of Health (2010)) followed market research methods. The data were weighted to account for quotas used in the sampling method. The results from the secondary statistical analysis using regression modelling reported

**Table 1** Numbers and percentages (in parentheses) of participants in each category of the six background variables, and for each participant and group overall (total)

	Cancer survivors (total)	Cancer survivors with no chronic condition	Cancer survivors with $\geq 1$ chronic condition	Participants with chronic conditions (total)	Participants with 1 chronic condition	Participants with $\geq 2$ chronic conditions	Healthy participants	Total
Total	780 (100)	413 (100)	367 (100)	1372 (100)	923 (100)	449 (100)	2740 (100)	4892 (100)
<i>Nation</i>								
England	503 (65)	255 (62)	248 (68)	876 (64)	584 (63)	292 (65)	1543 (56)	2922 (60)
Scotland	99 (13)	53 (13)	46 (13)	237 (17)	169 (18)	68 (15)	572 (21)	908 (19)
Wales	92 (12)	40 (10)	52 (14)	174 (13)	121 (13)	53 (12)	334 (12)	600 (12)
Northern Ireland	86 (11)	65 (16)	21 (6)	85 (6)	49 (5)	36 (8)	291 (11)	462 (9)
<i>Sex</i>								
Male	274 (35)	131 (32)	143 (39)	589 (43)	377 (41)	212 (47)	1026 (37)	1889 (39)
Female	506 (65)	282 (68)	224 (61)	783 (57)	546 (59)	237 (53)	1714 (63)	3003 (61)
<i>Age (in years)</i>								
30–34	20 (3)	18 (4)	2 (1)	69 (5)	56 (6)	13 (3)	444 (16)	533 (11)
35–39	30 (4)	22 (5)	8 (2)	80 (6)	65 (7)	15 (3)	388 (14)	498 (10)
40–44	55 (7)	37 (9)	18 (5)	116 (9)	95 (10)	21 (5)	366 (13)	537 (11)
45–49	53 (7)	36 (9)	17 (5)	125 (9)	91 (10)	34 (8)	346 (13)	524 (11)
50–54	93 (12)	45 (11)	48 (13)	127 (9)	80 (9)	47 (11)	297 (11)	517 (11)
55–59	101 (13)	58 (14)	43 (12)	185 (14)	136 (15)	49 (11)	264 (10)	550 (11)
60–64	96 (12)	36 (9)	60 (16)	178 (13)	111 (12)	67 (15)	200 (7)	474 (10)
65–69	145 (19)	79 (19)	66 (18)	285 (21)	176 (19)	109 (24)	258 (9)	688 (14)
70–74	101 (13)	41 (10)	60 (16)	121 (9)	73 (8)	48 (11)	101 (4)	323 (7)
75–79	53 (7)	26 (6)	27 (7)	63 (5)	30 (3)	33 (7)	45 (2)	161 (3)
80–84	27 (4)	12 (3)	15 (4)	19 (1)	9 (1)	10 (2)	23 (1)	69 (1)
85+	6 (1)	3 (1)	3 (1)	4 (0)	1 (0)	3 (1)	8 (0)	18 (0)
<i>Household structure</i>								
Alone	136 (17)	66 (16)	70 (19)	256 (19)	166 (18)	90 (20)	402 (15)	794 (16)
Partner and caring for children	72 (9)	48 (12)	24 (7)	171 (13)	129 (14)	42 (9)	686 (25)	929 (19)
Partner and not caring for children	469 (60)	243 (59)	226 (62)	746 (54)	491 (53)	255 (57)	1151 (42)	2366 (48)
No partner but caring for children	39 (5)	22 (5)	17 (5)	102 (7)	75 (8)	27 (6)	254 (9)	395 (8)
No partner and not caring for children, although not alone	64 (8)	34 (8)	30 (8)	97 (7)	62 (7)	35 (8)	247 (9)	408 (8)
<i>Carer status</i>								
Not a carer	675 (87)	364 (88)	311 (85)	1112 (81)	766 (83)	346 (77)	2318 (85)	4105 (84)
Primary carer	52 (7)	23 (6)	29 (8)	132 (10)	69 (8)	63 (14)	190 (7)	374 (8)
Occasional carer	53 (7)	26 (6)	27 (7)	128 (9)	88 (10)	40 (9)	232 (9)	413 (9)
<i>Type of interview</i>								
Online	627 (80)	308 (75)	319 (87)	1347 (98)	911 (99)	436 (97)	2470 (90)	4444 (91)
Telephone	153 (20)	105 (25)	48 (13)	25 (2)	12 (1)	13 (3)	270 (10)	448 (9)

Notes: Percents may not sum up exactly to 100 because of rounding.

in this paper are similar to the initial analysis using the weighted method.

## RESULTS

There were 4980 participants in the study. After initial analysis, only participants diagnosed in or before 2006 were considered as cancer survivors, and those diagnosed in 2007 were removed from the analysis, as it was assumed that they might not have completed primary cancer treatment at the time of completing the survey. This reduced the number of participants by 88 to 4892, of whom 780 were cancer survivors, 1372 had a chronic condition (other than cancer) and 2740 were 'healthy'. As there was a concern that some of the cancer survivors may have had ongoing or recurrent cancer, participants who self-reported that they were still affected

by cancer were excluded in one of the analysis models. There was no difference in the conclusions from this analysis, and therefore the results reported here are for the total remaining sample of cancer survivors. Overall, 34% of cancer survivors had breast cancer, 14% gynaecological cancers, 13% prostate cancer, 11% bowel cancers and the remainder one of 26 other types of cancer. Among the chronic conditions reported by the participants, including those who had cancer as well as a chronic condition, the most common were arthritis (57.6% of individuals with chronic conditions), heart disease (22.3%), diabetes (17.3%), asthma (16.6%) and osteoporosis (10.9%). It is interesting to note that 367 cancer survivors (47.1% of the total number of cancer survivors) had one or more chronic conditions in addition to their cancer (Table 1). Just under half (43.2%) of cancer survivors were first diagnosed with cancer within 5 years before the survey (10.1% in the first year, 2007, who were removed from the analysis, and

**Table 2** Numbers and percentages (in parentheses) of participants in each category of 12 of the outcome measures, by participant group and overall (total), and means and standard deviations for psychological well-being

<b>General health</b>	<b>Excellent</b>	<b>Very good</b>	<b>Good</b>	<b>Average</b>	<b>Poor or extremely poor</b>
Cancer survivors with no chronic condition	32 (8)	117 (28)	131 (32)	85 (21)	48 (12)
Cancer survivors with ≥ 1 chronic condition	4 (1)	43 (12)	87 (24)	118 (32)	115 (31)
Participants with 1 chronic condition	40 (4)	227 (25)	282 (31)	258 (28)	116 (13)
Participants with ≥ 2 chronic conditions	9 (2)	43 (10)	90 (20)	162 (36)	145 (32)
Healthy participants	360 (13)	1102 (40)	808 (30)	388 (14)	82 (3)
Total	445 (9)	1532 (31)	1398 (29)	1011 (21)	506 (10)

<b>Participation in vigorous activities</b>	<b>Not at all difficult</b>	<b>Only a little difficult</b>	<b>Somewhat difficult</b>	<b>Very difficult</b>	<b>Cannot do at all</b>
Cancer survivors with no chronic	61 (18)	100 (29)	87 (26)	38 (11)	55 (16)
Cancer survivors with ≥ 1 chronic	14 (5)	42 (15)	71 (25)	55 (19)	107 (37)
Participants with 1 chronic condition	98 (12)	204 (25)	252 (31)	100 (12)	156 (19)
Participants with ≥ 2 chronic conditions	27 (7)	45 (12)	87 (22)	70 (18)	160 (41)
Healthy participants	874 (36)	817 (33)	478 (20)	161 (7)	117 (5)
Total	1074 (25)	1208 (28)	975 (23)	424 (10)	595 (14)

<b>Physical well-being</b>	<b>1 (Not difficult)</b>	<b>2</b>	<b>3</b>	<b>4 (Very difficult)</b>
Cancer survivors with no chronic condition	272 (66)	41 (10)	59 (14)	41 (10)
Cancer survivors with ≥ 1 chronic condition	141 (38)	58 (16)	85 (23)	83 (23)
Participants with 1 chronic condition	575 (62)	139 (15)	122 (13)	87 (9)
Participants with ≥ 2 chronic conditions	157 (35)	80 (18)	101 (23)	111 (25)
Healthy participants	2325 (85)	182 (7)	156 (6)	77 (3)
Total	3470 (71)	500 (10)	523 (11)	399 (8)

<b>Aches and pain a problem</b>	<b>Yes</b>	<b>No</b>
Cancer survivors with no chronic condition	227 (55)	186 (45)
Cancer survivors with ≥ 1 chronic condition	279 (76)	88 (24)
Participants with 1 chronic condition	637 (69)	286 (31)
Participants with ≥ 2 chronic conditions	376 (84)	73 (16)
Healthy participants	1201 (44)	1539 (56)
Total	2720 (56)	2172 (44)

<b>Psychological well-being (range 1–5)</b>	<b>Mean</b>	<b>s.d.</b>
Cancer survivors with no chronic condition	2.43	0.80
Cancer survivors with ≥ 1 chronic condition	2.68	0.87
Participants with 1 chronic condition	2.58	0.79
Participants with ≥ 2 chronic condition	2.91	0.87
Healthy participants	2.41	0.74
Total	2.51	0.79

<b>Emotional well-being</b>	<b>1 (Good)</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5 (Poor)</b>
Cancer survivors with no chronic condition	95 (23)	83 (20)	74 (18)	68 (17)	93 (23)
Cancer survivors with ≥ 1 chronic condition	73 (20)	75 (20)	61 (17)	72 (20)	86 (23)
Participants with 1 chronic condition	166 (18)	218 (24)	171 (19)	183 (20)	185 (20)
Participants with ≥ 2 chronic conditions	77 (17)	83 (19)	73 (16)	97 (22)	119 (27)
Healthy participants	561 (21)	548 (20)	557 (20)	575 (21)	499 (18)
Total	972 (20)	1007 (21)	936 (19)	995 (20)	982 (20)

<b>Cognitive well-being</b>	<b>1 (Good)</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5 (Poor)</b>
Cancer survivors with no chronic condition	70 (17)	188 (46)	105 (25)	45 (11)	5 (1)
Cancer survivors with ≥ 1 chronic condition	40 (11)	171 (47)	110 (30)	33 (9)	13 (4)
Participants with 1 chronic condition	140 (15)	453 (49)	227 (25)	90 (10)	13 (1)
Participants with ≥ 2 chronic conditions	70 (16)	177 (39)	148 (33)	46 (10)	8 (2)
Healthy participants	528 (19)	1374 (50)	646 (24)	152 (6)	40 (2)
Total	848 (17)	2363 (48)	1236 (25)	366 (8)	79 (2)

<b>Health prevented working preferred occupation</b>	<b>Disagree strongly</b>	<b>Disagree a little</b>	<b>Neither disagree nor agree</b>	<b>Agree a little</b>	<b>Agree strongly</b>
Cancer survivors with no chronic condition	230 (56)	40 (10)	58 (14)	34 (8)	51 (12)
Cancer survivors with ≥ 1 chronic condition	143 (39)	29 (8)	47 (13)	49 (13)	99 (27)
Participants with 1 chronic condition	525 (57)	90 (10)	123 (13)	78 (9)	107 (12)
Participants with ≥ 2 chronic conditions	169 (38)	38 (9)	74 (17)	61 (14)	107 (24)
Healthy participants	2043 (75)	200 (7)	228 (8)	126 (5)	143 (5)
Total	3110 (64)	397 (8)	530 (11)	348 (7)	507 (10)

**Table 2** (Continued)

<b>Number of professionals consulted in the last 12 months</b>	<b>None</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4 or more</b>
Cancer survivors with no chronic condition	31 (8)	175 (42)	145 (35)	50 (12)	12 (3)
Cancer survivors with $\geq 1$ chronic condition	15 (4)	101 (28)	162 (44)	68 (19)	21 (6)
Participants with 1 chronic condition	62 (7)	447 (48)	288 (31)	100 (11)	26 (3)
Participants with $\geq 2$ chronic conditions	6 (1)	140 (31)	202 (45)	85 (19)	16 (4)
Healthy participants	710 (26)	1320 (48)	540 (20)	144 (5)	26 (1)
Total	824 (17)	2183 (45)	1337 (27)	447 (9)	101 (2)
<b>Number of health services used in the last 12 months</b>	<b>None</b>	<b>1</b>	<b>2</b>	<b>3</b>	
Cancer survivors with no chronic condition	264 (64)	92 (22)	42 (10)	15 (4)	
Cancer survivors with $\geq 1$ chronic condition	189 (52)	103 (28)	48 (13)	27 (7)	
Participants with 1 chronic condition	655 (71)	184 (20)	64 (7)	20 (2)	
Participants with $\geq 2$ chronic conditions	227 (51)	114 (25)	72 (16)	36 (8)	
Healthy participants	2195 (80)	405 (15)	108 (4)	32 (1)	
Total	3530 (72)	898 (18)	334 (7)	130 (3)	
<b>Number of times seen a doctor or other health-care professional in the last 12 months</b>	<b>None</b>	<b>One visit</b>	<b>Two or three visits</b>	<b>Four to nine visits</b>	<b>Ten or more visits</b>
Cancer survivors with no chronic condition	63 (15)	70 (17)	131 (32)	112 (27)	37 (9)
Cancer survivors with $\geq 1$ chronic condition	26 (7)	37 (10)	79 (22)	132 (36)	93 (25)
One chronic condition	91 (10)	170 (18)	258 (28)	305 (33)	99 (11)
Participants with $\geq 2$ chronic conditions	25 (6)	38 (9)	85 (19)	205 (46)	96 (21)
Healthy participants	865 (32)	615 (22)	725 (27)	428 (16)	107 (4)
Total	1070 (22)	930 (19)	1278 (26)	1182 (24)	432 (9)
<b>Problems paying for everyday items</b>	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	
Cancer survivors with no chronic condition	284 (69)	64 (16)	42 (10)	23 (6)	
Cancer survivors with $\geq 1$ chronic condition	220 (60)	62 (17)	56 (15)	29 (8)	
Participants with 1 chronic condition	593 (64)	158 (17)	119 (13)	53 (6)	
Participants with $\geq 2$ chronic conditions	235 (52)	87 (19)	81 (18)	46 (10)	
Healthy participants	1765 (52)	544 (19)	296 (18)	135 (10)	
Total	3097 (64)	915 (20)	594 (11)	286 (5)	
<b>Problems with debt</b>	<b>Not in debt</b>	<b>In debt but not worried about it</b>	<b>In debt and worried about it</b>		
Cancer survivors with no chronic condition	283 (71)	60 (15)	56 (14)		
Cancer survivors with $\geq 1$ chronic condition	243 (70)	62 (18)	42 (12)		
Participants with 1 chronic condition	561 (63)	204 (23)	131 (15)		
Participants with $\geq 2$ chronic conditions	236 (57)	116 (28)	66 (16)		
Healthy participants	1542 (59)	709 (27)	375 (14)		
Total	2865 (61)	1151 (25)	670 (14)		

Notes: (1) 0.01 Level of significance for all measures, (2) percents may not sum up exactly to 100 because of rounding; (3) analyses of participation in vigorous activities and problems with debt are based on 4276 and 4686 cases, respectively (cases with missing values excluded). Moreover, for technical reasons, those aged 85 years and over (18 cases) were excluded from the analysis of debt.

then 9.4%, 8.0%, 8.9% and 6.8% in each of the next four years, respectively). A further 28.2% were diagnosed between 5 and 10 years before the survey (7.1%, 5.9%, 6.5%, 5.2% and 3.6% in each subsequent year, respectively) and 28.6% were diagnosed more than 10 years before the survey. The online survey was completed by 4444 (90.8%) participants and 448 (9.2%) completed the survey by telephone interview.

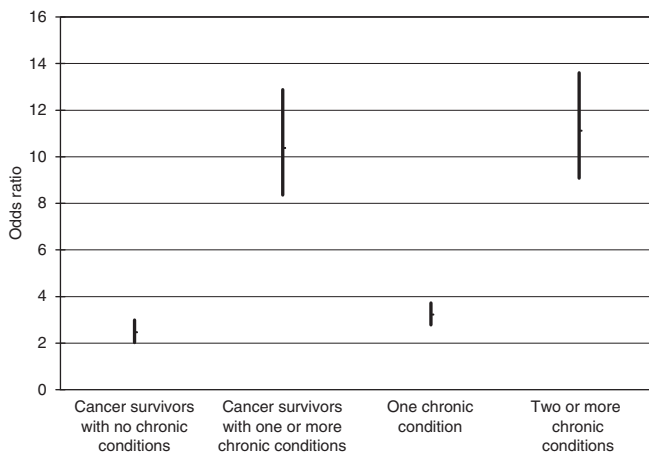
Demographic and background characteristics of participants are shown in Table 1. In the sample, cancer survivors were different from healthy participants in certain key characteristics; for example, a greater proportion of cancer survivors lived in England (64% of all cancer survivors vs 56% of healthy participants). Cancer survivors were older than participants with other chronic diseases and had a greater proportion of females (65 vs 57%); this reflects the fact that the predominant group among cancer survivors are women with breast cancer (Maddams *et al*, 2009), and a smaller proportion of people who used the online survey (80 vs 98%).

The distribution of responses to the 13 outcomes measures is shown in Table 2. Cancer survivors reported poorer health and well-being outcomes across all 13 measures compared with healthy individuals. The  $\chi^2$ -tests and the one-way ANOVA test for a difference in means are significant, indicating that before controlling for the background variables there are some differences between the groups for all of the outcome measures (Table 2). Cancer survivors were significantly more likely to report being in average or poor general health (47% of all cancer survivors vs 17% of healthy participants), find participation in vigorous activities very difficult or report not being able to do them at all (33% of all cancer survivors vs 11% of healthy participants), find performing physical activities very difficult (16 vs 3%), report aches and pains as a problem (65 vs 44%), poor emotional well-being (23 vs 18%) and poor cognitive functioning (2.3 vs 1.5%). In addition, cancer survivors were more likely to indicate that their health had prevented them from working in their preferred occupation (19% of cancer survivors vs 5% of healthy participants), and to use

**Table 3** Estimated adjusted odds ratios for the participant groups compared with healthy participants for 12 of the outcome measures and estimated difference in means for psychological well-being, with corresponding 95% confidence intervals in parentheses

	Cancer survivor with no chronic conditions	Cancer survivor with ≥1 chronic condition	Participants with 1 chronic condition	Participants with ≥2 chronic conditions
General health	2.46 (2.03, 2.99)	10.37 (8.36, 12.88)	3.22 (2.78, 3.72)	11.11 (9.08, 13.60)
Participation in vigorous activities	2.10 (1.70, 2.58)	6.36 (5.02, 8.05)	3.06 (2.63, 3.56)	7.31 (5.91, 9.04)
Physical well-being	2.76 (2.18, 3.48)	8.92 (7.09, 11.21)	3.52 (2.95, 4.20)	10.05 (8.11, 12.47)
Aches and pain a problem	1.67 (1.34, 2.08)	4.68 (3.57, 6.13)	3.12 (2.63, 3.71)	7.58 (5.72, 10.04)
Emotional well-being	1.37 (1.13, 1.66)	1.93 (1.57, 2.36)	1.36 (1.19, 1.57)	2.18 (1.80, 2.63)
Cognitive well-being	1.60 (1.31, 1.96)	2.38 (1.92, 2.94)	1.58 (1.36, 1.82)	2.19 (1.80, 2.67)
Health prevented working in preferred occupation	2.72 (2.20, 3.36)	6.92 (5.55, 8.62)	2.50 (2.13, 2.94)	6.25 (5.09, 7.66)
Number of health-care professionals consulted	3.34 (2.74, 4.08)	6.83 (5.51, 8.48)	2.86 (2.47, 3.32)	6.57 (5.38, 8.03)
Number of health services used in the last 12 months	2.73 (2.17, 3.42)	5.21 (4.13, 6.58)	2.00 (1.67, 2.39)	5.71 (4.60, 7.09)
Number of times seen a doctor or other health-care professional in the last 12 months	2.95 (2.43, 3.58)	7.87 (6.35, 9.74)	3.15 (2.73, 3.63)	7.94 (6.51, 9.69)
Problems paying for everyday items	1.45 (1.14, 1.83)	2.69 (2.13, 3.41)	1.41 (1.2, 1.66)	3.12 (2.52, 3.85)
In debt but not worried about it vs not in debt	0.85 (0.62, 1.18)	1.18 (0.86, 1.64)	1.08 (0.88, 1.33)	1.93 (1.47, 2.54)
In debt and worried about it vs not in debt	1.81 (1.28, 2.57)	2.17 (1.46, 3.24)	1.56 (1.21, 2.00)	2.76 (1.95, 3.92)
Psychological well-being	0.17 <sup>a</sup> (0.09, 0.26)	0.44 <sup>a</sup> (0.35, 0.53)	0.24 <sup>a</sup> (0.18, 0.30)	0.60 <sup>a</sup> (0.52, 0.68)

<sup>a</sup>Estimated difference in means, as a linear regression model was used for psychological well-being. An adjusted odds ratio significantly greater than one for a particular group indicates that the individuals in that group are in poorer health than the reference group of healthy individuals.



**Figure 2** Estimated adjusted odds ratios with corresponding CIs for general health.

health services: 4.2% of cancer survivors consulted four or more health professionals in the past 12 months (vs 1% of healthy participants), and nearly 17% visited a doctor or other health-care professional 10 times or more over the past 12 months (vs 4% of healthy participants).

The results from fitting multiple logistic regression models to control for the six background variables (nation, sex, age household structure, carer status and type of interview) are presented in Table 3 and Appendix 1, and the general pattern is illustrated in Figure 2, which presents the estimated adjusted odds ratios with corresponding confidence intervals (CIs) for General Health. Table 3 presents the estimated odds ratios with corresponding 95% CIs for the various groups when compared with the healthy, after adjusting for the six background variables. The adjusted odds ratios for cancer survivors with no chronic conditions compared with healthy participants ranged from 1.37 (95% CI: 1.31–1.96) for emotional well-being to 3.34 (95% CI: 2.74–4.08) for number of health professionals consulted (see second column of Table 3). The adjusted odds ratios for participants with one chronic condition compared with healthy participants were similar to those for cancer survivors with no chronic conditions, ranging from 1.36 (95% CI: 1.19–1.57)

for emotional well-being to 3.52 (95% CI: 2.95–4.20) for physical well-being (see fourth column of Table 3). The adjusted odds ratios for cancer survivors with one or more chronic conditions compared with healthy participants ranged from 1.93 (95% CI: 1.57–2.36) for emotional well-being to 10.37 (95% CI: 8.36–12.88) for general health. Furthermore, the adjusted odds ratios for cancer survivors with one or more chronic condition were similar to those for participants with two or more chronic conditions as can be seen by comparing the third and fifth columns of Table 3.

An adjusted odds ratio significantly greater than one for a particular group indicates that the individuals in that group are in poorer health than the reference group of healthy individuals. Therefore, inspection of Table 3 reveals that, generally, cancer survivors are in significantly poorer health than healthy participants on the health outcome measures, indicating that cancer survivors do not return to or attain full health after completing primary cancer treatment. Cancer survivors instead are not significantly different from people with chronic conditions. Therefore, although many cancer survivors are medically cured of their cancer, their health status is similar to that of someone with a chronic condition. For example, cancer survivors with no chronic conditions are not significantly different from individuals with one chronic condition, and cancer survivors with at least one other chronic condition are not significantly different from individuals with two or more chronic conditions (odd ratios approximately equal within each pair of groups). However, the group with multiple conditions is significantly worse than the group with only one condition (cancer or one of the specified chronic conditions), which in turn is significantly worse than the healthy group (odds ratios for the group with multiple conditions greater than those for the group with one condition, which in turn are greater than one). The exceptions are as follows:

1. Emotional well-being, where the pattern is the same for all participant groups, but not all the differences are significant.
2. Participation in vigorous activities, where cancer survivors with no chronic conditions are significantly better than individuals with one chronic condition.
3. Aches and pains, a problem where there appears to be an ordering where individuals with two or more chronic conditions are worse than cancer survivors with at least one

other chronic condition, who are worse than individuals with one chronic condition, who in turn are worse than cancer survivors with no chronic conditions, who are worse than healthy, although not all the comparisons are significantly different. Debt, where there are no differences between the four groups with conditions, all of which are significantly worse than the healthy. Psychological well-being, where individuals with two or more chronic conditions are significantly worse than cancer survivors who have at least one chronic condition.

## DISCUSSION

### Principal findings

This is the first study of UK citizens to examine the health and well-being of cancer survivors comparing these with healthy individuals and individuals with one or more serious chronic health conditions. The study reveals that cancer survivors appear to have ongoing health problems, reporting poor general health, physical well-being and pain. They also report making greater use of health services than individuals who do not have a cancer diagnosis or chronic condition. The differences extend beyond health *per se* and into social and economic dimensions of life with differences also evident in the ability to work in a preferred occupation and in relation to debt. Differences are not accounted for by other factors such as age or household structure or by individuals who have active cancer. It appears that although many cancer survivors report good health, a substantial proportion of between 10 and 20% of cancer survivors with no other chronic condition may have serious ongoing poor health and disability and for those with an additional chronic condition this may be as high as 25–30%; for example, 12% of cancer survivors with no chronic conditions and 31% of survivors with one or more chronic conditions reported being in poor or extremely poor health and 16% and 37% of cancer survivors, respectively, reported not being able to participate in vigorous activities at all (Table 2).

These data confirm the finding by Hewitt *et al* (2003) that a medical history of cancer at least doubles an individual's likelihood of poor health, and disability among US patients also appears to be true of UK cancer survivors. Our study also confirms the findings from other studies of specific cancer groups, which have examined the long-term health profiles of individuals, again revealing a substantial proportion of individuals with ongoing health problems and long-term effects of cancer treatment with evidence of increased use of health services and adverse effects on employment for individuals (Bradley and Bednarek, 2002; Short *et al*, 2005; Van de Poll-Franse *et al*, 2006; Jansen *et al*, 2010). In our study, it appears that a small group of cancer survivors are heavy users of health services.

### Strengths and weaknesses of the study

The study has limitations. Although efforts were made to secure a representative sample of the UK population through recruitment using the online panel, supplemented with online and telephone recruitment, the approach used may mean that the study is not fully representative of cancer survivors, and although this is the largest UK-based study to date, it is still relatively small. There may have been a selection effect, with those in worse health or better health, self-selecting to participate in the survey. However, there is nothing to suggest that such an effect exists, and the distributions of some key variables are similar to those observed in the UK population. Moreover, there is no reason to think that any selection effect present may differ between different subgroups in this study. There were some differences between the study

subgroups across the background variables (Table 1), which, although they were controlled for in the regression analysis, are acknowledged, and in particular that the healthy group was younger than the disease groups. The study relied on self-reported information relating to diagnosis, the presence or absence of health conditions and health status and the presence of active cancer, and no clinical data were available relating to types of cancer or cancer treatment received by participants. However, the data are very similar to those reported in the National Health Interview Study, which suggests that the findings outlined are not just confined to the US or UK cancer survivors.

Further research is needed into the specific problems that people experience in the years following a cancer diagnosis, which might lead to the identification of those most at risk of ongoing problems, so that support can be provided to individuals. Consensus is needed over the best measures to use in monitoring the health outcomes for cancer survivors as quality-of-life measures developed for evaluating the impact of cancer treatment may not be sensitive to all issues cancer survivors experience such as ongoing physical, psychological and social problems or the long-term physical consequences of cancer treatment and comorbidity. It is essential in the future to be able to compare results across studies and populations. The findings of this study point to the need for long-term prospective studies of cancer survivors. Work to identify the most cost-effective ways of supporting individuals following cancer treatment is also needed.

### Implications for clinicians and policymakers

Until recently, little attention has been paid to the ongoing needs of people who have completed treatment with curative intent; the emphasis has been placed on receiving timely and effective treatment. This study indicates that there is a need to consider the ongoing health of cancer survivors and provide support and early intervention for problems following cancer treatment and for problems that may emerge after treatment has been completed, which in some cases may emerge years later as a consequence of cancer treatment. There is a need to understand in detail the immediate and late consequences of cancer treatment on individuals, as well as the inter-relationship between cancer treatment and preexisting or subsequent development of comorbidities, as this study indicates that these may incur the risk of significant health challenges to individuals. Little or no data exist as to who may be at risk of developing ongoing problems or as to how such problems might be prevented or ameliorated. This study indicates that a starting point for identifying risk of ongoing problems is comorbidity and the existence of other chronic conditions. Therefore, identification of these at-risk individuals should be incorporated into the ongoing assessment and support of cancer survivors.

The profiles of cancer survivors in our study are remarkably similar to individuals with chronic or long-term health conditions. Given the current emphasis on providing support for such individuals and redesigning health services around the needs of individuals with long-term conditions in UK health policy, our study provides evidence that individuals who have a diagnosis of cancer are an important group in this respect. To date, beyond recognition that current models of cancer follow-up are ineffective, there is as yet little progress in designing models of care that might be better tailored to meet individuals' long-term needs. There may be significant value in evaluating whether models of supported self-management and rehabilitation used in long-term conditions care could be transferred to individuals with cancer (Department of Health, 2005, 2007, 2009).

Given that the National Cancer Survivorship Initiative continues to give important emphasis in the Cancer Outcomes Strategy for Cancer (Department of Health, 2011), these data are timely as they provide evidence that cancer survivors have ongoing health needs



that are not currently being addressed. Alongside recent publication of data indicating the growing number of individuals living with a cancer diagnosis, this study provides a basis for a new focus of attention on the long-term experience of cancer and its impact on physical, functional and social well-being.

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Appendix 1

Estimated adjusted odds ratios for six background variables and the participant groups compared with healthy participants for 12 of the outcome measures and estimated difference in means for psychological well-being, with corresponding 95% CIs in parentheses

Table with 13 columns: General health, Participation in vigorous activities, Physical well-being, Aches and pains a problem, Emotional well-being, Cognitive well-being, Health prevented working in preferred occupation, No. of health-care professionals consulted in the last 12 months, No. of health services used in the last 12 months, No. of times seen a doctor or other health-care professionals in the last 12 months, Problems paying for everyday items, In debt, not worried vs not in debt, In debt and worried vs not in debt, Psychological well-being. Rows include Region (Scotland, Wales, Northern Ireland), Sex (Male), Age (in years) (35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85+), Household structure (Partner and caring for children, Partner and not caring for children, No partner but caring for children, No partner and not caring for children, although not alone), Gender status (Primary carer, Occasional carer), Type of interview (Telephone), and Subject group (Cancer survivor with no chronic conditions, Cancer survivor with at least one chronic condition, One chronic condition, More than two chronic conditions).

Notes: \*\*0.01 Level of significance; \*0.05 level of significance; (a)for technical reasons, those aged 85 years and above (18 cases) were excluded from the analysis of debt; (b)estimated difference in means, as a linear regression model was used for psychological well-being. Age was introduced as a continuous variable in this model.