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# Levels of acute health service use among cancer survivors in the United Kingdom

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ABSTRACT

*Background:* In the United Kingdom, there are approximately two million cancer survivors (3.2% of the entire population), composed of groups of people in different phases of survivorship and with different health service needs. The aim of this study was to quantify the level of acute health service utilisation by cancer survivors in the UK, according to tumour type, age, sex, time since diagnosis, and time until death.

*Methods:* Linked national cancer registry and hospital activity data were analysed. The data covered all cancer-related admissions to public hospitals operated by the National Health Service in England occurring in 2006 among people diagnosed with cancer in the period 1990–2006. The intensity of cancer-related health service utilisation was categorised as 'none', 'low' (up to 10% of an individual's time), or 'high' (>10% of an individual's time), among groups defined by time since diagnosis and time until death. Results were extrapolated from the population of England in 2006 (51 million) to that of the UK in 2008 (61 million).

*Findings:* Sixty one thousand of the two million cancer survivors (3%) were in the 'high' utilisation category; 240,000 (12%) were in the 'low' category; 1.70 million (85%) had no cancer-related hospital admissions. 147,000 cancer survivors (7%) were in the last year of their life, and it was this group that had the highest levels of hospital utilisation. 1.57 million cancer survivors (78%) were more than 1 year from both diagnosis and death, and had no cancer related hospital admissions.

*Interpretation:* A considerable proportion of cancer survivors in the UK have a high level of hospital utilisation soon after diagnosis or before death, but the large majority of them are neither recently diagnosed nor near the end of their life, and do not utilise acute health services for cancer-related care.



## 1. Introduction

Cancer prevalence, the proportion of a population that has been diagnosed with cancer, is one measure of the cancer burden on society. The prevalent population comprises 'cancer survivors' – those people alive following a diagnosis of cancer from some point in their past. The broad definition of cancer survivors includes those recently diagnosed, in active treatment, in remission, receiving treatment for recurrence, in end of life care, and those who are cured.

Previous work has shown that there are approximately two million cancer survivors in the United Kingdom and that in recent years this number has increased by approximately 3% per annum,[1] largely due to an ageing population, earlier

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detection of cancers, and improved treatment regimes leading to increased survival. The Cancer Reform Strategy[2] led to the establishment in 2008 of a National Cancer Survivorship Initiative to focus on the needs of the growing population of survivors in England. As observed cancer survival increases, so does the number of long term survivors. For many people diagnosed with cancer, it is no longer considered the death sentence it once was.[3,4] Indeed, it has been argued that in many cases cancer may be better described as a chronic illness, i.e. one characterised by a prolonged duration and a recurring nature.[5] It is useful therefore to go beyond a simple enumeration of survivors, since this tells us only a limited amount about the cancer burden in terms of (a) the personal psychosocial and physical burden to the individual survivor; and (b) the resource implications to the health service and society at large.

Prevalence is often estimated directly from cancer registry data, and it is easy to disaggregate the prevalence estimates according to year of diagnosis or equivalently time since diagnosis.[6–13] Intuitively this appears a good way to broadly categorise cancer survivors – certainly the first year following diagnosis is likely to be one of the most traumatic physically and emotionally. However, in the medium and long term after diagnosis, survivorship is likely to vary greatly across individuals, and it may not be sufficient to classify the population of cancer survivors simply by time since diagnosis.

This work presents an analysis of a linked cancer registry and health service activity dataset for England. A set of survivorship 'states' are defined in terms of four temporal 'phases of survivorship' (using time since diagnosis and time until death) and intensity of acute health service utilisation. Using person-time methods, the number of survivors in each of these states at the end of 2008 is estimated. Results are presented in a novel way using bespoke graphics.

## 2. Methods

### 2.1. Data

The analysis was based on two linked datasets. The English national merged cancer registry dataset, which featured patient and diagnostic information relating to all cancers diagnosed between 1990 and 2006 and recorded by the eight regional population-based cancer registries in England, was linked at the patient level to the English national Hospital Episode Statistics (HES) dataset[14] which contained patient, clinical, and administrative details for in-patients and day case patients treated in any hospital operated by the 166 National Health Service (NHS) providers in England. The linkage algorithm was 'rules-based' and used national health service number (which is unique to each patient), date of birth, date of death where appropriate, sex and postcode of residence. Each HES record defines a complete episode of care under a given consultant in a given NHS facility, and a patient's journey from admission to discharge may comprise many such episodes.

The national cancer registry dataset was used to define a cohort of cancer survivors who had been diagnosed with a malignant neoplasm (other than non-melanoma skin cancer) in the period 1990–2006, and were alive for at least some portion of 2006. Sub-cohorts were defined according to type of cancer: colon, rectum, and anus cancers (ICD-10 C18-C21); lung, bronchus, and trachea cancers (ICD-10 C33-C34); prostate cancer (ICD-10 C61); and female breast cancer (ICD-10 C50). Details of all hospital episodes of care occurring in 2006 for these cancer survivors were extracted from the linked dataset. Episodes were included in the analysis if they were 'cancer related', in that at least one of the 14 recorded hospital diagnosis codes was for a malignancy other than non-melanoma skin cancer.

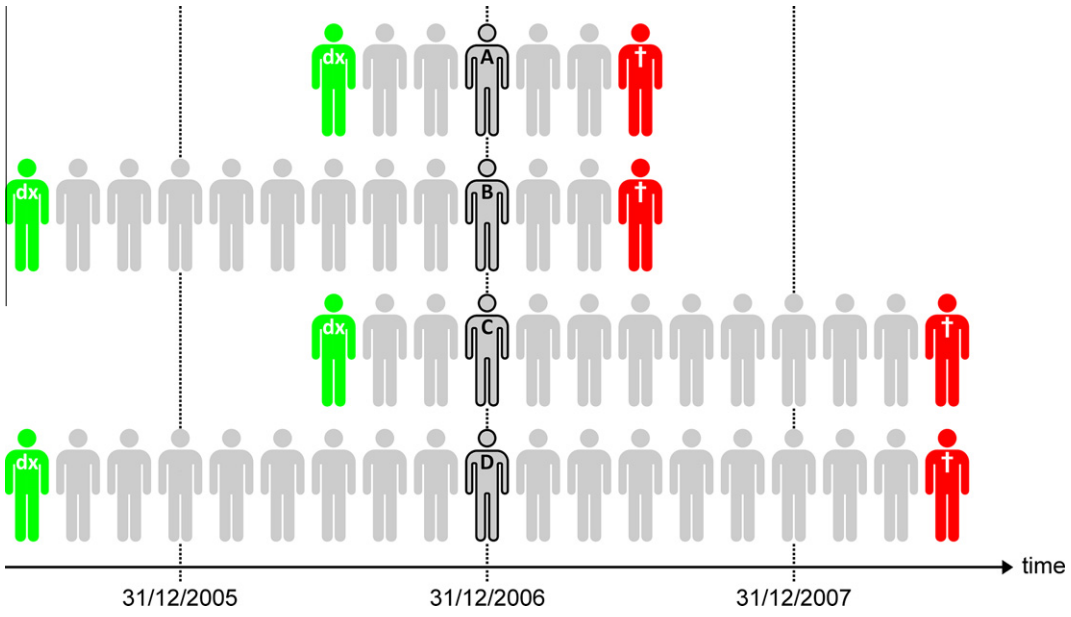


**Fig. 1 – Survivors in temporal phases A–D on 31st December 2006. dx = diagnosis; † = death; A–D = temporal phase of survivorship as defined in Box 1.**

### 2.2. Survivorship states

Four distinct temporal phases of survivorship (Box 1 and Fig. 1) were defined according to time since diagnosis and time until death:

| Box 1: temporal phases of survivorship | |
|---|---|
| Phase A | Less than 1 year from death and less than 1 year from diagnosis |
| Phase B | Less than 1 year from death and more than 1 year from diagnosis |
| Phase C | More than 1 year from death and less than 1 year from diagnosis |
| Phase D | More than 1 year from death and more than 1 year from diagnosis |

For each survivor, the person-time for which they were prevalent in 2006 (i.e. that which was post-diagnosis and pre-death and overlapped the calendar year 2006) was split into segments according to the time points at which they moved between temporal phases or broad age bands (chosen to be 0–44, 45–64, and ⩾65 years). Since death notifications were available for survivors in the cancer registry dataset up to the end of 2008, it was possible to identify the points in time during 2006 at which any survivors entering the last year of their life did so. This person-time splitting procedure was executed using the SAS software package (SAS Institute Inc., Cary, NC, United States of America) and a series of programmes developed by JM for this task, similar to the programme *Lexis.sas* by Carstensen.[15]

Intensity of acute health service utilisation was defined in each segment of person-time according to the combined duration of cancer related hospital episodes that occurred. It was considered to be "high" if hospital activity accounted for more than 10% of the person-time segment; it was considered to be "low" if hospital activity accounted for some, but not more than 10%, of the segment; and a separate category was reserved for those segments of person-time which contained no hospital activity. There were, therefore, 12 possible survivorship states defined according to temporal phase and intensity of acute health service utilisation (Fig. 2). The total amount of person-time spent by the population of survivors in each of these states was calculated separately for each tumour group and sex.

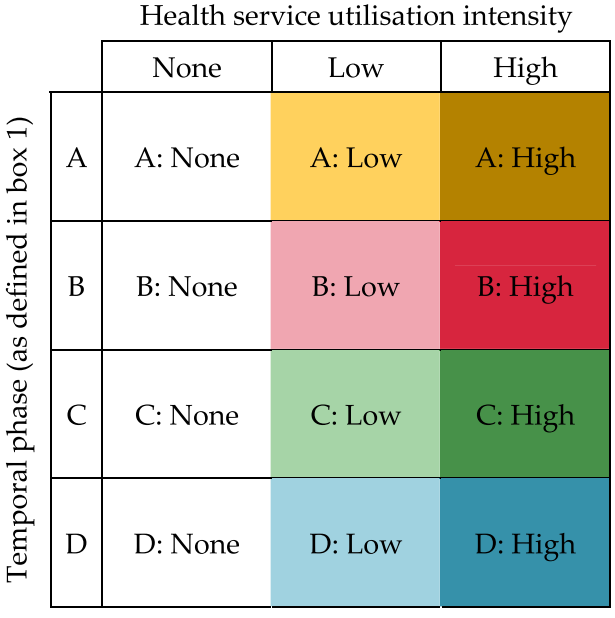


**Fig. 2 – Survivorship states defined by time since diagnosis, time until death and health service utilisation. Key to Figs. 3 and 4.**

Under certain assumptions, the proportion of total population person-time spent in each survivorship state is equal to the proportion of the prevalent population in that state at a given point in time during the analysis period (see Supplementary web extra material). Using this fact, the summed population person-time in our analysis was used to estimate the proportion of survivors in each state at the end of 2006.

### 2.3. Extrapolation to complete prevalence in 2008

In order to use our person-time analysis for the year 2006 to estimate the proportion of survivors in each survivorship state at the end of 2008 (the most recent estimate of prevalence in the UK[1]), it was assumed that the distribution of survivors between states did not change between 2006 and 2008.

The cancer registry dataset contained diagnoses made in the period 1990–2006. The person-time analysis for 2006 therefore completely described only those survivors diagnosed up to 16 years previously (16-year prevalence). By definition, survivors more than 16 years from diagnosis are in either temporal phase B or D. It was assumed that the distribution of survivors between these two phases was the same for those more than 16 years from diagnosis as it was for those between 15 and 16 years from diagnosis. It was also assumed that the relative numbers of survivors with an acute health service utilisation intensity of "high", "low", or "none" in each temporal phase B or D were the same for survivors greater than 16 years from diagnosis as they were for those in that phase no more than 16 years from diagnosis.

## 3. Results

Results are presented graphically in Figs. 3 and 4. Each figure contains a set of square tiles, with each tile representing cancer survivors of a given cancer type, sex, and broad age group. The density of the overlaid male or female icons is proportional to the total number of survivors represented by the tile. Four horizontal divisions mark the proportion of survivors in each of the four temporal phases (Box 1) and, in each phase, three vertical divisions mark the proportion of survivors in each category of acute health service utilisation. The resulting 12 areas are coloured to indicate the different survivorship states represented (Fig. 2).

These figures aim to present a large amount of data in a clean and simple manner, allowing for an immediate high level analysis, as well as facilitating in-depth study and easy comparison across cancer types, age groups, and sexes. The design was inspired by the work of the Dutch artist Piet Mondrian (1872–1944) who simplified visual compositions to three primary colours and a grid of black lines on a white background.[16] The underlying counts of survivors are given in Table 1, and the corresponding proportions in Table 2.

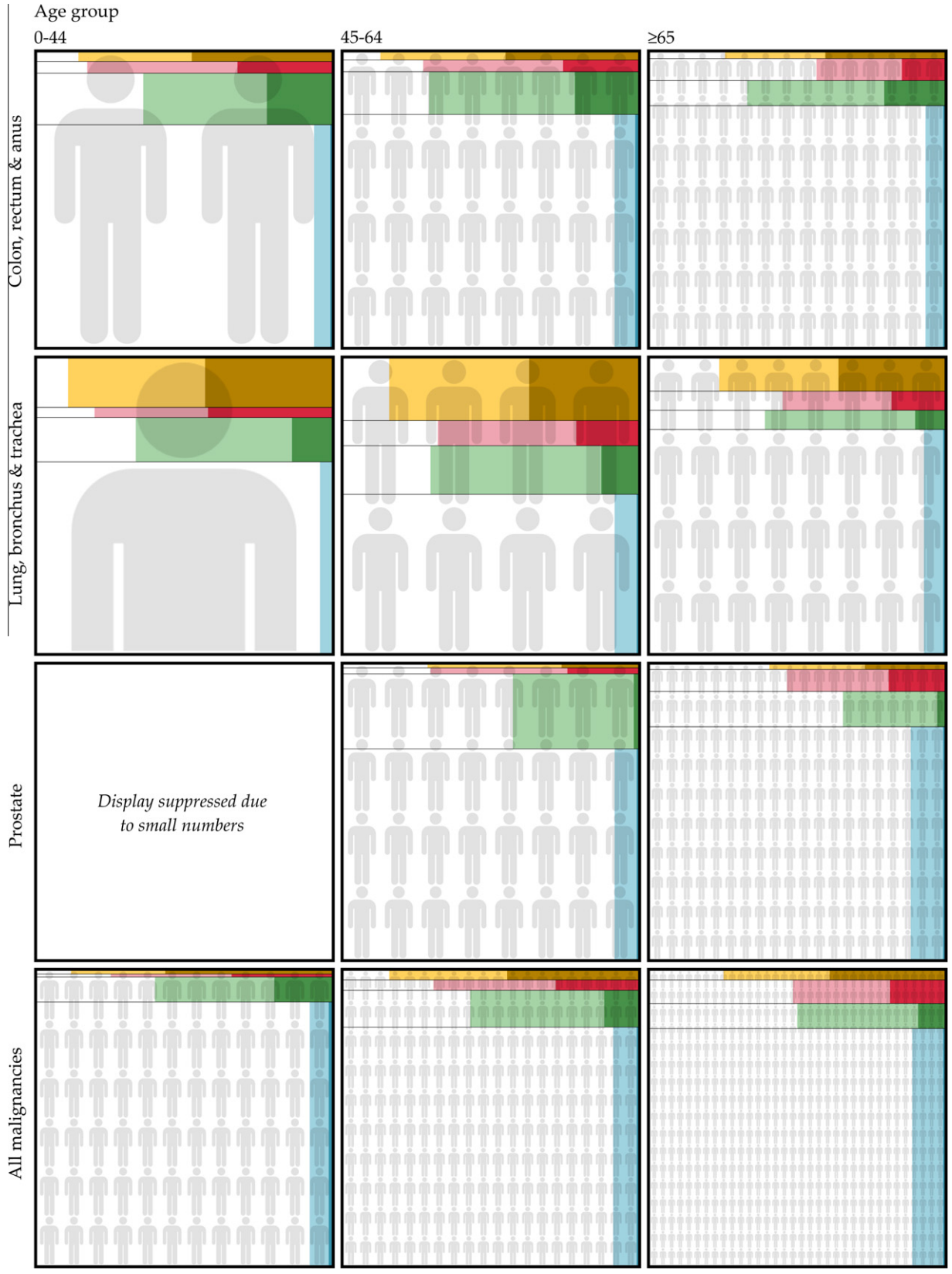


**Fig. 3 – Male cancer survivors, UK, 2008; by age, type of cancer and survivorship state. In each tile, the rows from top to bottom correspond to the 4 temporal phases of survivorship (A-D) respectively, with the vertical bands from left to right corresponding to states of increasing acute health service utilisation (see Fig. 2 and Box 1 for definitions). Each male icon represents approximately 1,000 cancer survivors (exact counts are in Table 1). The proportion of survivors in temporal phase D (more than 1 year from both diagnosis and death) and with a 'high' level of acute health service utilisation (the rightmost area of the bottom row) may be too small to be visible.**

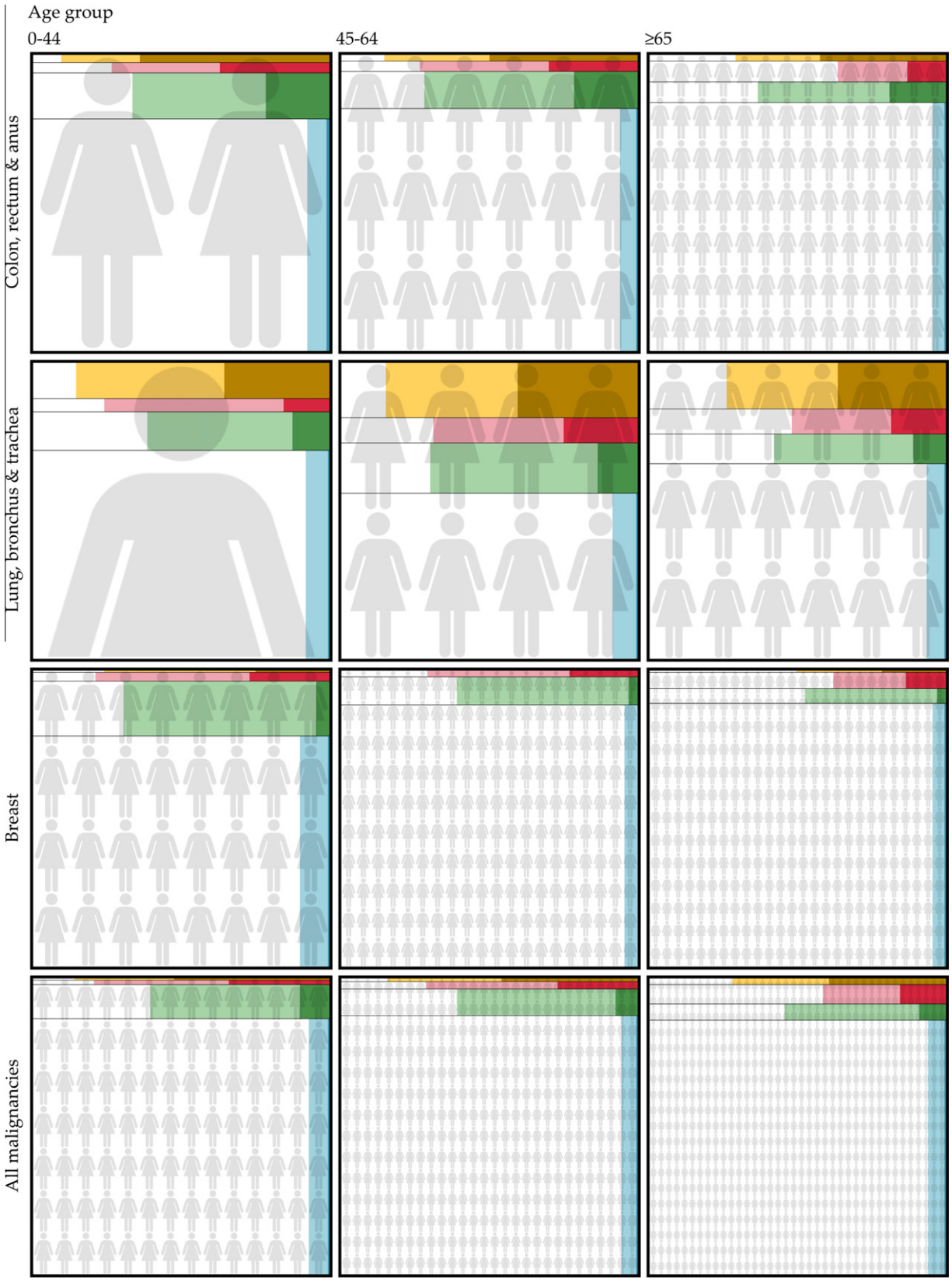


**Fig. 4 – Female cancer survivors, UK, 2008; by age, type of cancer and survivorship state. In each tile, the rows from top to bottom correspond to the 4 temporal phases of survivorship (A-D) respectively, with the vertical bands from left to right corresponding to states of increasing acute health service utilisation (see Fig. 2 and Box 1 for definitions). Each female icon represents approximately 1,000 cancer survivors (exact counts are in Table 1). The proportion of survivors in temporal phase**

**D (more than 1 year from both diagnosis and death) and with a 'high' level of acute health service utilisation (the rightmost area of the bottom row) may be too small to be visible. Similarly, the proportion of breast cancer survivors in temporal phase A (within one year of both diagnosis and death – the top row) may be too small to be visible.**

**Table 1 – Number of survivors in the United Kingdom, 2008. By temporal phase of survivorship[a] and intensity of cancer related hospitalisation[b].**

| Sex | | | Age group | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | 0–44 Intensity of hospitalisation | | | | 45–64 Intensity of hospitalisation | | | | ⩾65 Intensity of hospitalisation | | | |
| | Type of Cancer | Temporal phase | None | Low | High | Total | None | Low | High | Total | None | Low | High | Total |
| Male | | | | | | | | | | | | | | |
| | Colon, rectum and anus | A | <10 | 20 | 30 | 60 | 80 | 260 | 270 | 610 | 530 | 710 | 840 | 2,080 |
| | | B | 10 | 40 | 30 | 80 | 290 | 510 | 270 | 1,060 | 4,120 | 2,130 | 1,070 | 7,320 |
| | | C | 130 | 150 | 80 | 360 | 1,050 | 1,820 | 790 | 3,670 | 2,590 | 3,650 | 1,590 | 7,840 |
| | | D | 1,490 | 90 | <10 | 1,590 | 18,760 | 1,430 | 160 | 20,350 | 72,400 | 4,700 | 410 | 77,520 |
| | | Total | 1,640 | 310 | 150 | 2,090 | 20,180 | 4,010 | 1,500 | 25,690 | 79,640 | 11,200 | 3,910 | 94,750 |
| | Lung, bronchus and trachea | A | <10 | 30 | 30 | 70 | 210 | 660 | 520 | 1,400 | 830 | 1,420 | 1,260 | 3,500 |
| | | B | <10 | <10 | <10 | 20 | 180 | 260 | 120 | 550 | 930 | 770 | 370 | 2,070 |
| | | C | 20 | 40 | <10 | 70 | 320 | 630 | 130 | 1,090 | 830 | 1,090 | 220 | 2,130 |
| | | D | 280 | 10 | <10 | 290 | 3,310 | 270 | 20 | 3,600 | 22,360 | 1,500 | 90 | 23,950 |
| | | Total | 310 | 90 | 50 | 440 | 4,030 | 1,820 | 790 | 6,640 | 24,950 | 4,780 | 1,940 | 31,660 |
| | Prostate | A | <10 | <10 | <10 | <10 | 80 | 130 | 70 | 280 | 1,110 | 890 | 740 | 2,740 |
| | | B | <10 | <10 | <10 | <10 | 220 | 350 | 180 | 750 | 7,800 | 5,860 | 3,210 | 16,880 |
| | | C | 20 | 10 | <10 | 40 | 5,020 | 3,590 | 140 | 8,740 | 17,190 | 8,370 | 600 | 26,160 |
| | | D | 120 | 10 | <10 | 130 | 22,830 | 1,830 | 80 | 24,740 | 152,850 | 18,960 | 1,150 | 172,970 |
| | | Total | 140 | 30 | 10 | 180 | 28,150 | 5,890 | 470 | 34,510 | 178,960 | 34,080 | 5,700 | 218,740 |
| | All malignant neoplasms | A | 80 | 210 | 360 | 650 | 880 | 2,260 | 2,500 | 5,640 | 4,180 | 6,170 | 6,680 | 17,030 |
| | | B | 220 | 360 | 300 | 880 | 1,960 | 2,680 | 1,790 | 6,430 | 21,210 | 14,480 | 8,060 | 43,750 |
| | | C | 2,400 | 2,410 | 1,150 | 5,950 | 10,330 | 10,810 | 2,740 | 23,880 | 24,500 | 19,820 | 4,270 | 48,600 |
| | | D | 59,200 | 4,020 | 560 | 63,780 | 142,560 | 12,260 | 1,150 | 155,970 | 398,000 | 45,800 | 2,840 | 446,640 |
| | | Total | 61,890 | 6,990 | 2,370 | 71,250 | 155,730 | 28,010 | 8,180 | 191,920 | 447,890 | 86,270 | 21,850 | 556,020 |
| Female | | | | | | | | | | | | | | |
| | Colon, rectum and anus | A | <10 | 10 | 30 | 50 | 50 | 140 | 190 | 390 | 510 | 500 | 750 | 1,750 |
| | | B | 20 | 30 | 30 | 80 | 180 | 300 | 200 | 680 | 4,010 | 1,470 | 820 | 6,300 |
| | | C | 110 | 150 | 70 | 330 | 710 | 1,260 | 540 | 2,510 | 2,310 | 2,790 | 1,190 | 6,290 |
| | | D | 1,550 | 110 | 10 | 1,680 | 15,140 | 910 | 100 | 16,150 | 73,780 | 3,010 | 310 | 77,090 |
| | | Total | 1,690 | 300 | 150 | 2,130 | 16,080 | 2,610 | 1,030 | 19,720 | 80,600 | 7,760 | 3,070 | 91,430 |
| | Lung, bronchus and trachea | A | <10 | 30 | 20 | 60 | 160 | 480 | 440 | 1,080 | 750 | 1,060 | 1,030 | 2,840 |
| | | B | <10 | 10 | <10 | 20 | 150 | 220 | 120 | 500 | 760 | 520 | 290 | 1,570 |
| | | C | 30 | 30 | <10 | 70 | 300 | 570 | 130 | 1,000 | 780 | 860 | 200 | 1,850 |
| | | D | 340 | 30 | <10 | 370 | 3,040 | 260 | 20 | 3,320 | 11,320 | 740 | 40 | 12,090 |
| | | Total | 380 | 110 | 40 | 530 | 3,660 | 1,530 | 710 | 5,900 | 13,600 | 3,180 | 1,560 | 18,350 |
| | Breast | A | 30 | 60 | 30 | 120 | 130 | 250 | 140 | 520 | 830 | 480 | 360 | 1,670 |
| | | B | 150 | 370 | 190 | 710 | 1,260 | 2,110 | 1,020 | 4,390 | 11,200 | 4,390 | 2,400 | 17,990 |
| | | C | 1,430 | 3,060 | 210 | 4,700 | 7,610 | 11,430 | 610 | 19,660 | 8,250 | 7,020 | 500 | 15,770 |
| | | D | 17,950 | 1,870 | 80 | 19,890 | 174,890 | 8,240 | 380 | 183,510 | 268,030 | 11,200 | 840 | 280,070 |
| | | Total | 19,560 | 5,360 | 510 | 25,430 | 183,890 | 22,030 | 2,150 | 208,080 | 288,300 | 23,090 | 4,100 | 315,490 |
| | All malignant neoplasms | A | 100 | 230 | 360 | 690 | 670 | 1,650 | 1,970 | 4,290 | 3,570 | 4,100 | 5,010 | 12,680 |
| | | B | 310 | 680 | 510 | 1,490 | 2,690 | 4,230 | 2,550 | 9,470 | 25,610 | 11,570 | 6,890 | 44,070 |
| | | C | 4,390 | 5,620 | 1,140 | 11,160 | 13,460 | 18,490 | 2,560 | 34,510 | 17,200 | 17,270 | 3,510 | 37,970 |
| | | D | 76,500 | 5,240 | 540 | 82,280 | 318,620 | 17,370 | 1,200 | 337,190 | 573,070 | 32,000 | 2,460 | 607,520 |
| | | Total | 81,300 | 11,770 | 2,550 | 95,620 | 335,440 | 41,730 | 8,280 | 385,460 | 619,440 | 64,940 | 17,870 | 702,250 |

Numbers may not sum to group totals since all are rounded to the nearest 10. Numbers less than 10 are suppressed.

[a] Phase A = less than 1 year from death and less than 1 year from diagnosis; phase B = less than 1 year from death and more than 1 year from diagnosis; phase C = more than 1 year from death and less than 1 year from diagnosis; phase D = more than 1 year from death and more than 1 year from diagnosis.

[b] None = no time is spent as an admitted hospital patient; low = time spent as an admitted hospital patient accounts for some, but no more than 10% of, person time; high = time spent as an admitted hospital patient accounts for more than 10% of person time.

**Table 2 – Percentage of survivors in the UK, 2008. By temporal phase of survivorship[a] and intensity of cancer related hospitalisation[b].**

| Sex | | | Age group | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | 0–44 Intensity of hospitalisation | | | | 45–64 Intensity of hospitalisation | | | | ⩾65 Intensity of hospitalisation | | | |
| | Type of Cancer | Temporal phase | None | Low | High | Total | None | Low | High | Total | None | Low | High | Total |
| Male | | | | | | | | | | | | | | |
| | Colon, rectum and anus | A | 0.4 | 1.2 | 1.5 | 3.1 | 0.3 | 1.0 | 1.1 | 2.4 | 0.6 | 0.8 | 0.9 | 2.2 |
| | | B | 0.7 | 1.9 | 1.2 | 3.8 | 1.1 | 2.0 | 1.1 | 4.1 | 4.3 | 2.2 | 1.1 | 7.7 |
| | | C | 6.2 | 7.3 | 3.8 | 17.3 | 4.1 | 7.1 | 3.1 | 14.3 | 2.7 | 3.9 | 1.7 | 8.3 |
| | | D | 71.1 | 4.3 | 0.5 | 75.8 | 73.0 | 5.5 | 0.6 | 79.2 | 76.4 | 5.0 | 0.4 | 81.8 |
| | | Total | 78.3 | 14.7 | 7.0 | 100.0 | 78.6 | 15.6 | 5.8 | 100.0 | 84.0 | 11.8 | 4.1 | 100.0 |
| | Lung, bronchus and trachea | A | 1.7 | 7.6 | 7.0 | 16.3 | 3.2 | 10.0 | 7.9 | 21.1 | 2.6 | 4.5 | 4.0 | 11.1 |
| | | B | 0.7 | 1.4 | 1.5 | 3.6 | 2.7 | 3.9 | 1.8 | 8.4 | 2.9 | 2.4 | 1.2 | 6.5 |
| | | C | 5.0 | 7.9 | 2.1 | 15.0 | 4.9 | 9.5 | 2.0 | 16.4 | 2.6 | 3.4 | 0.7 | 6.7 |
| | | D | 62.4 | 2.6 | 0.2 | 65.1 | 49.9 | 4.0 | 0.2 | 54.2 | 70.6 | 4.7 | 0.3 | 75.7 |
| | | Total | 69.8 | 19.5 | 10.7 | 100.0 | 60.7 | 27.5 | 11.9 | 100.0 | 78.8 | 15.1 | 6.1 | 100.0 |
| | Prostate | A | 0.0 | 0.5 | 1.0 | 1.6 | 0.2 | 0.4 | 0.2 | 0.8 | 0.5 | 0.4 | 0.3 | 1.3 |
| | | B | 0.8 | 0.5 | 1.3 | 2.6 | 0.6 | 1.0 | 0.5 | 2.2 | 3.6 | 2.7 | 1.5 | 7.7 |
| | | C | 13.2 | 7.3 | 2.4 | 22.9 | 14.5 | 10.4 | 0.4 | 25.3 | 7.9 | 3.8 | 0.3 | 12.0 |
| | | D | 64.5 | 6.8 | 1.7 | 73.0 | 66.2 | 5.3 | 0.2 | 71.7 | 69.9 | 8.7 | 0.5 | 79.1 |
| | | Total | 78.5 | 15.2 | 6.4 | 100.0 | 81.6 | 17.1 | 1.4 | 100.0 | 81.8 | 15.6 | 2.6 | 100.0 |
| | All malignant neoplasms | A | 0.1 | 0.3 | 0.5 | 0.9 | 0.5 | 1.2 | 1.3 | 2.9 | 0.8 | 1.1 | 1.2 | 3.1 |
| | | B | 0.3 | 0.5 | 0.4 | 1.2 | 1.0 | 1.4 | 0.9 | 3.4 | 3.8 | 2.6 | 1.4 | 7.9 |
| | | C | 3.4 | 3.4 | 1.6 | 8.3 | 5.4 | 5.6 | 1.4 | 12.4 | 4.4 | 3.6 | 0.8 | 8.7 |
| | | D | 83.1 | 5.6 | 0.8 | 89.5 | 74.3 | 6.4 | 0.6 | 81.3 | 71.6 | 8.2 | 0.5 | 80.3 |
| | | Total | 86.9 | 9.8 | 3.3 | 100.0 | 81.1 | 14.6 | 4.3 | 100.0 | 80.6 | 15.5 | 3.9 | 100.0 |
| Female | | | | | | | | | | | | | | |
| | Colon, rectum and anus | A | 0.2 | 0.6 | 1.5 | 2.4 | 0.3 | 0.7 | 1.0 | 2.0 | 0.6 | 0.5 | 0.8 | 1.9 |
| | | B | 1.0 | 1.3 | 1.4 | 3.7 | 0.9 | 1.5 | 1.0 | 3.5 | 4.4 | 1.6 | 0.9 | 6.9 |
| | | C | 5.2 | 7.0 | 3.4 | 15.5 | 3.6 | 6.4 | 2.7 | 12.7 | 2.5 | 3.0 | 1.3 | 6.9 |
| | | D | 72.6 | 5.2 | 0.6 | 78.5 | 76.8 | 4.6 | 0.5 | 81.9 | 80.7 | 3.3 | 0.3 | 84.3 |
| | | Total | 79.0 | 14.1 | 6.9 | 100.0 | 81.5 | 13.2 | 5.2 | 100.0 | 88.2 | 8.5 | 3.4 | 100.0 |
| | Lung, bronchus and trachea | A | 1.8 | 6.1 | 4.3 | 12.2 | 2.8 | 8.2 | 7.4 | 18.4 | 4.1 | 5.8 | 5.6 | 15.5 |
| | | B | 1.1 | 2.7 | 0.7 | 4.5 | 2.6 | 3.7 | 2.1 | 8.4 | 4.1 | 2.9 | 1.6 | 8.6 |
| | | C | 5.1 | 6.4 | 1.6 | 13.1 | 5.2 | 9.6 | 2.3 | 17.0 | 4.2 | 4.7 | 1.1 | 10.1 |
| | | D | 64.7 | 5.2 | 0.3 | 70.2 | 51.4 | 4.4 | 0.3 | 56.2 | 61.7 | 4.0 | 0.2 | 65.9 |
| | | Total | 72.6 | 20.4 | 7.0 | 100.0 | 62.0 | 25.9 | 12.1 | 100.0 | 74.1 | 17.3 | 8.5 | 100.0 |
| | Breast | A | 0.1 | 0.2 | 0.1 | 0.5 | 0.1 | 0.1 | 0.1 | 0.2 | 0.3 | 0.2 | 0.1 | 0.5 |
| | | B | 0.6 | 1.5 | 0.8 | 2.8 | 0.6 | 1.0 | 0.5 | 2.1 | 3.5 | 1.4 | 0.8 | 5.7 |
| | | C | 5.6 | 12.0 | 0.8 | 18.5 | 3.7 | 5.5 | 0.3 | 9.4 | 2.6 | 2.2 | 0.2 | 5.0 |
| | | D | 70.6 | 7.3 | 0.3 | 78.2 | 84.1 | 4.0 | 0.2 | 88.2 | 85.0 | 3.5 | 0.3 | 88.8 |
| | | Total | 76.9 | 21.1 | 2.0 | 100.0 | 88.4 | 10.6 | 1.0 | 100.0 | 91.4 | 7.3 | 1.3 | 100.0 |
| | All malignant neoplasms | A | 0.1 | 0.2 | 0.4 | 0.7 | 0.2 | 0.4 | 0.5 | 1.1 | 0.5 | 0.6 | 0.7 | 1.8 |
| | | B | 0.3 | 0.7 | 0.5 | 1.6 | 0.7 | 1.1 | 0.7 | 2.5 | 3.6 | 1.6 | 1.0 | 6.3 |
| | | C | 4.6 | 5.9 | 1.2 | 11.7 | 3.5 | 4.8 | 0.7 | 9.0 | 2.4 | 2.5 | 0.5 | 5.4 |
| | | D | 80.0 | 5.5 | 0.6 | 86.0 | 82.7 | 4.5 | 0.3 | 87.5 | 81.6 | 4.6 | 0.3 | 86.5 |
| | | Total | 85.0 | 12.3 | 2.7 | 100.0 | 87.0 | 10.8 | 2.1 | 100.0 | 88.2 | 9.2 | 2.5 | 100.0 |

Percentages sum to 100% for each type of cancer/age group (subject to rounding errors).

[a] Phase A = less than 1 year from death and less than 1 year from diagnosis; phase B = less than 1 year from death and more than 1 year from diagnosis; phase C = more than 1 year from death and less than 1 year from diagnosis; phase D = more than 1 year from death and more than 1 year from diagnosis.

[b] None = no time is spent as an admitted hospital patient; low = time spent as an admitted hospital patient accounts for some, but no more than 10% of, person time; high = time spent as an admitted hospital patient accounts for more than 10% of person time.

At the end of 2008, approximately 81% of all male survivors and 87% of all female survivors were more than 1 year from diagnosis and more than 1 year from death. There was little variation in these proportions by age, except for male survivors aged under 45 years for whom this proportion rose to 90%. The proportion of lung cancer survivors who were more than 1 year from both diagnosis and death was markedly lower (72% of male survivors and 64% of female survivors). There was little acute health service utilisation among survivors in this phase, regardless of age or type of cancer. Overall, 1.57 million cancer survivors in the UK at the end of 2008 (78%) were more than 1 year from both diagnosis and death, and had no cancer related hospital admissions.

240,000 of the two million cancer survivors in the UK (14.8% of male survivors and 10.0% of female survivors) were in the 'low' acute health care utilisation category. Sixty one thousand (4.0% of male survivors and 2.4% of female survivors) were in the 'high' category. The proportion of lung cancer survivors in the 'high' category was much larger (7.2% of males and 9.3% of females), particularly in the age group 45–64 years where the proportion rose to around 12%. Conversely, only 1.2% of female breast cancer survivors had a 'high' level of acute health care utilisation.

147,000 cancer survivors were in the last year of their life (9.0% of male survivors and 6.2% of female survivors). It was these survivors who had the highest intensity of cancer related acute health service utilisation, particularly those who were also in the first year since diagnosis. Forty one percent of the 41,000 survivors who were less than 1 year from both diagnosis and death had a high intensity of acute health service utilisation, compared with 19% of the 106,000 survivors who were in the last year of their life but more than 1 year from diagnosis.

## 4. Discussion

The linked dataset allowed an analysis of all recorded episodes of hospital in-patient or day case healthcare among registered cancer survivors in England during 2006. A person-time approach allowed us to quantify the intensity of hospitalisation, and the associated burden on cancer survivors and the health service, by considering the amount of time spent in hospital, rather than just the number of admissions.

The hospital activity data featured details of all types of in-patient and day case care delivered to cancer survivors, not just that which related to cancer. Each record had up to 14 diagnostic codes (using the ICD-10 classification) and 12 operation procedure codes, with the first of each of these codes intended to indicate the primary diagnosis or intent of the treatment. For simplicity, we categorised episodes as 'related to cancer' or 'not related to cancer' according to the diagnostic codes only. This was an intentionally broad categorisation, designed to take account of the wide range of health problems associated with cancer and the side effects of its treatment. Nonetheless the specificity of the definition is unproven and it is not possible to say exactly which kinds of treatment following a cancer diagnosis are included. However, an analysis of the complementary 'non-cancer related' care (not presented here) indicates that the cancer related definition does achieve its goal by removing some of the background hospitalisation experienced by this population. The proportion of time spent by cancer survivors in hospital for non-cancer related care was much lower than for cancer related care, and was generally constant regardless of time since diagnosis. In this analysis, therefore, 'cancer related' hospitalisation may be considered as that directly or indirectly caused by, or in some way associated with, a cancer diagnosis.

Some survivors will be diagnosed with additional primary cancers some time after their first diagnosis. Indeed, many studies have shown elevated cancer incidence rates in those previously diagnosed with cancer compared with the general population[17,18] and the prevalence of multiple malignancies among cancer survivors has been shown to be around 7%.[19] However, treatment received for subsequent cancers is indistinguishable in this analysis from that received for the initial cancer, a fact to be born in mind when considering the 'time since diagnosis' dimension of this study.

A small number of survivors in the cancer registry data will have had a diagnosis pre-1990 as well as in the period 1990–2006. However, since details of diagnoses made before 1990 were not available in the linked dataset, it was necessary to assume that all survivors alive during 2006 had their first cancer diagnosis in the period 1990–2006. The effect of this assumption is a possible small re-distribution of survivors between the tumour sites studied, but is not considered to be a significant limitation.

Survivorship states were defined according to time since diagnosis, time until death, and proportion of time spent admitted to hospital. The first year following diagnosis was considered to be potentially important, since this is the time during which cancer patients receive initial treatment, the success of which may significantly affect their subsequent health and well-being. The final year before death was also considered to be potentially important since for many people who die from cancer there is a period of health deterioration in the months beforehand. For some survivors post-diagnosis survival is short – a separate temporal phase was therefore defined by the intersection of the first year following diagnosis and the last year of life. The period of survivorship which is more than 1 year from both diagnosis and death also defined a separate temporal phase and may be characterised by periods of remission, relapse, disease monitoring, and/or eventual 'cure'.

Cancer prevalence is driven by cancer incidence and survival, and the distribution of survivors between temporal phases of survivorship can largely be explained by incidence and survival characteristics. For example, lung cancer has a universally poor prognosis (age-standardised five-year relative survival rates in England and Wales are under 10%[20]) and accordingly a large proportion of lung cancer survivors were less than 1 year from both diagnosis and death. On the other hand, one quarter of prostate cancer survivors aged 45–64 were less than 1 year from diagnosis but not less than 1 year from death, reflecting the relatively good prognosis of this disease and the rapidly increasing incidence rates brought about by the diagnostic use of the PSA test since the early 1990s.[21]

In recent decades, the number of cancer survivors in the UK has grown steadily each year.[1] The distribution of survivors between temporal phases, and the intensity of acute health service utilisation within them, provides an insight into what is meant by the term 'cancer survivor', especially given the current national survivorship initiatives in the UK and the movement towards understanding cancer as a chronic illness. For example, the majority of UK cancer survivors (1.69 million of the 2.00 million) are more than 1 year from both diagnosis and death, and the degree of acute health service utilisation in this phase is small – 1.57 million are in a period characterised by no cancer related acute health service utilisation and these survivors account for 78% of all UK can-

cer survivors. Cancer survivors can now realistically expect to live longer, but this analysis suggests that the primary burden of cancer on the health service still comes from survivors in the first year following diagnosis and/or near the end of their life. The term 'cancer survivor' was originally proposed by the US National Coalition for Cancer Survivorship in 1986 at a time when "cancer was a disease that people needed to learn to fight" but has, according to some, become "so muddy that...a new definition is needed".[22] Alternative terms include people 'living with or beyond cancer' or 'cancer patients'. However, this analysis has shown that survivorship is heterogeneous, and finding a single term to usefully define everyone who has ever been diagnosed with cancer may not be possible.

A limitation of this work is that it only considered *admitted* hospital episodes (in-patients and day cases). Visits to general practitioner surgeries and other outpatient clinics are not captured in this analysis, but much of the observation and monitoring of survivors (especially those who are more than 1 year from both diagnosis and death) is carried out in outpatient clinics.[23] Neither does this analysis consider the personal psychosocial or general health burden of cancer on survivors – the trauma of being diagnosed with a life-threatening illness such as cancer is associated with post traumatic stress disorder, depression, and other mental disorders,[24,25] and cancer survivors have been found to have poorer general health outcomes than individuals who have not been diagnosed with cancer.[26] Cancer survivors are also likely to face day-to-day struggles (such as financial, emotional, relationship, and employment difficulties) even if they have no need for treatment in hospital.[27,28] These issues present significant burdens to cancer survivors and should be kept in mind when considering the distribution of survivors between the states defined in this analysis.

The extent to which the population of cancer survivors in the UK is receiving care and treatment in hospital is central to understanding the burden of cancer on society. The findings contained here will be of interest to health service providers keen to quantify the volume of acute health care administered to cancer survivors, and the associated financial burden, as well as to survivors themselves.

## Conflict of interest statement

None declared.

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The corresponding author, Jacob Maddams, had full access to all the data in this study and had final responsibility for the decision to submit the manuscript for publication.

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## Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.ejca.2011.04.015.

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