



# Unmet supportive care needs of breast, colorectal and testicular cancer survivors in the first 8 months post primary treatment: A prospective longitudinal survey

Lynn Batehup<sup>1</sup>  | Heather Gage<sup>2</sup> | Peter Williams<sup>3</sup> | Alison Richardson<sup>4</sup> | Katerina Porter<sup>1</sup> | Peter Simmonds<sup>5</sup> | Elizabeth Lawson<sup>1</sup> | Lynne Dodson<sup>1</sup> | Nicola Davies<sup>6</sup> | Richard Wagland<sup>1</sup>  | Jane Winter<sup>7,8</sup> | Andrew Turner<sup>9</sup> | Jessica Corner<sup>10</sup>

<sup>1</sup>Health Sciences, University of Southampton, Tremona Road, Southampton, UK

<sup>2</sup>Surrey Health Economics Centre, School of Bioscience & Medicine, University of Surrey, Guildford, UK

<sup>3</sup>School of Mathematics, University of Surrey, Guildford, UK

<sup>4</sup>University of Southampton and University Hospital Southampton NHS Foundation Trust, Southampton General Hospital, Southampton, UK

<sup>5</sup>Cancer Research UK, Clinical Research Unit, University of Southampton, Southampton, UK

<sup>6</sup>Health Psychology Consultancy Ltd., 12 Hitchin Lane, Clifton, Shefford, UK

<sup>7</sup>University of Southampton NHS Trust, Tremona Road, Southampton, Hampshire, UK

<sup>8</sup>Wessex Cancer Alliance, Oakley Road, Southampton, Hampshire, UK

<sup>9</sup>Centre For Intelligent Healthcare, Coventry University, The Hub, Jordan Well, Coventry CV1 5T, UK

<sup>10</sup>The University of Nottingham, University Park, Nottingham, UK

## Correspondence

Lynn Batehup, Health Sciences, University of Southampton, Southampton S017 1BJ, UK.  
Email: l.batehup@soton.ac.uk

## Abstract

**Objectives:** To explore the supportive care needs of cancer survivors, the characteristics of patients with high levels of unmet need, changes in unmet need after treatment ends and differences in unmet needs of breast, colorectal and testicular survivors.

**Methods:** The method used was a prospective longitudinal mailed survey. Unmet needs, measured by 25-item modified Cancer Survivors Unmet Needs survey at baseline (immediately post-treatment) and 8 months later, were analysed descriptively.

**Results:** Of 434 breast, 186 colorectal and 75 testicular patients responding at baseline, 56.2%, 65.6% and 50.7%, respectively, had no unmet needs, the top decile having  $\geq 10$  (breast) or seven (colorectal and testicular) different needs and seven different unmet needs. The most frequently reported unmet need (all groups) was fear of cancer recurrence. Unmet needs fell significantly at 8 months for breast patients. Some patients reported new needs. Needs were lowest amongst colorectal survivors and differed between the three groups. Higher levels of unmet needs (breast and colorectal) were associated with having had chemotherapy.

**Conclusion:** Most survivors reported few unmet needs, but a small proportion have persisting or emerging needs. Routine or regular monitoring of unmet needs is required so that healthcare professionals can deliver personalised care based on individual needs, preferences and circumstances.

## KEYWORDS

breast cancer, colorectal cancer, oncology, survivors, testicular cancer, unmet needs

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**1 | INTRODUCTION**

Improvements in early detection and more effective treatments have led to increased cancer survival rates in most regions of the world (Allemani et al., 2018). However, this population of cancer survivors (Macmillan Cancer Support, 2017) may experience detrimental impacts on quality of life, psychological morbidity and unmet needs as a result of their cancer and treatment (Palmer et al., 2017; Smith et al., 2018). This paper focusses on unmet supportive care needs that were reported by breast, colorectal and testicular cancer survivors. The data were gathered as part of a larger study (Batehup et al., 2017) that was conducted at a time when policy and practice regarding follow-up after cancer treatment in the British National Health Service (NHS) was changing (Davies & Batehup, 2011). A shift was proposed from traditional hospital clinic-based follow-up for all patients to patient stratification, based on a clinical assessment of individual patient needs. Patients judged to have ongoing problems or complex conditions continued to receive clinic follow-up whilst others are provided with information for self-management and the opportunity to contact specialist nurses by telephone with their concerns and questions (patient triggered follow-up). All usual surveillance tests continue (<http://www.evidence.nhs.uk/qipp>). This change was largely prompted by resourcing pressures in hospital outpatient departments that were increasing waiting times for cancer treatment (Davies & Batehup, 2011). Whilst there is little evidence that clinic follow-up improves recurrence detection rates (Centre for Reviews and Dissemination, 2007; Kimman et al., 2007; Montgomery et al., 2007), concerns exist that removal or reduction of outpatient attendance may increase anxiety amongst survivors and result in their needs not being addressed (Chapman et al., 2009). Hence, the unmet supportive care needs of survivors in three tumour groups within a large cancer centre in United Kingdom were evaluated to inform future service developments. Breast and colorectal pathways were selected because these are high volume services; testicular patients were added because they are an under-researched group.

Available evidence on unmet needs of cancer survivors is inconclusive (Harrison et al., 2009; Harrison et al., 2010; Willems et al., 2015; Wylie et al., 2013), and little comparative information is available. This paper reports findings from a study that aimed to improve understanding of unmet needs to inform practice through (1) an assessment of the prevalence of different types of unmet needs reported by breast, colorectal and testicular cancer survivors at completion of treatment and how these changed over the subsequent

8 months and (2) an investigation of the characteristics of survivors reporting high levels of unmet need so that support can be targeted. The study also enabled a comparison of the unmet needs of breast, colorectal and testicular survivors.

**2 | METHODS**

A longitudinal survey of breast, colorectal and testicular cancer patients was carried out in two cohorts (before and after the introduction of patient triggered follow-up) between April 2011 and August 2013. Salient details can be found elsewhere (Batehup et al., 2017). Almost all (90%) of those in the patient triggered follow-up cohort were receiving outpatient follow up at the start of the study so the cohorts were combined for the analysis. Researchers used a review of records, including chemotherapy and radiotherapy treatments and multidisciplinary team meetings to identify patients aged 18 years and over who were coming to completion of treatment with curative intent and entering follow-up. Permission was obtained from clinicians to approach their patients. Patients were excluded if they were unable to complete the necessary questionnaires or had a second cancer diagnosed during treatment. Informed consent was obtained from all individual participants. Approval was obtained from the Ethics Committee of the NHS Trust involved. Guidance from the National Research Ethics Service advised this was a service evaluation. The procedures in this study adhere to the tenets of the Declaration of Helsinki.

Structured questionnaires were mailed to patients after final treatment (T0) and four (T1), eight (T2) and 12 (T3) months later. Three reminders were sent to non-responders. Only responses at T0 and T2 are included in this paper. Participants' experience at these points reflect needs after primary treatment and over a period when awareness of emotional and psychosocial effects of cancer survivorship grows. Some participants recruited at the end of the project were not sent questionnaires at T2, and some questionnaires that were sent and returned were not analysed due to study time constraints, thereby reducing the sample size at T2.

**2.1 | Baseline questionnaire and data collection**

Participant demographics were collected at baseline, including gender, age, relationship status, education, employment status and comorbid conditions. Clinical information on treatments received, dates and

**TABLE 1** Cancer survivors unmet supportive care needs survey

Item number	Domain	Item, CaSUN Need Description I need:	
1	Information (INFO)	Up to date information	
2		Information relevant for my partner/family	
3		Understandable information	
4	Comprehensive Cancer Care (CCC)	The very best medical care	
5		Local health services available when I require them	
6		To feel I can manage my health together with my health team	
7		My doctors to talk to each other to coordinate my care	
8		My complaints regarding my care to be properly addressed	
9		Existential Survivorship (ES)	To reduce stress in my life
10			Help to cope with my concerns that my cancer will recur
11			Emotional support for me
14	To make new relationships		
15	To talk to other survivors like me		
16	Help to handle the topic of cancer in social/work situation		
17	To adjust to changes to the way I feel about my body		
12	Relationships (REL)		To know how to support my family/partner
13		Help to deal with the impact of cancer on my relationships	
18		Help to deal with problems with my sex life	
19	Coping (COP)	To move on with my life	
20		To deal with my belief that nothing bad will happen again	
21		For others to acknowledge the impact of cancer on my life	
22		Help to cope with others' expectations of me as a survivor	
23		To make decisions about my life in uncertain times	
24		Help with my spiritual beliefs	
25		To make my life count	

*Note:* Response options for each item were as follows: Not applicable; No need; I have the need, but it is being met; Yes, I have the need and it is not being met (i.e., an unmet need). Three items were omitted from the 28 items assessing need: reference to car parking was removed from the Comprehensive Cancer Care domain because patients found it irrelevant. The two items comprising the Quality of Life domains were dropped because quality of life was measured by other instruments in the parent study. A new Coping domain was created with seven items from the 14 items Existential Survivorship domain. Unmet needs were rated Strong/Moderate/Weak. Scoring and interpretation of CaSUN was carried out according to published guidance (Hodgkinson et al., 2007). As domains contain different numbers of items, the mean number of needs were analysed. Missing CaSUN items were recoded as follows for calculating domain and total unmet needs: within each of the five domains where at least one, but not all, items were completed, each missing item was set equal to the proportion of unmet needs amongst the non-missing items in that domain. If only one domain had all items missing, each item was assigned the proportion of unmet needs amongst all non-missing items in the other four domains. If two or more domains had all items missing, these domains and the total unmet needs were set as missing (irrespective of how many of the 25 items had been answered).

recurrences, were extracted from clinical notes (with consent). Post-code was used to derive the Index of Multiple Deprivation (Ministry of Housing, Communities and Local Government, Office of National Statistics, Index of Multiple Deprivation, 2015).

## 2.2 | Measuring supportive care needs

Supportive care needs in the preceding month were measured at each time point using the Cancer Survivors Unmet Needs Survey (CaSUN)

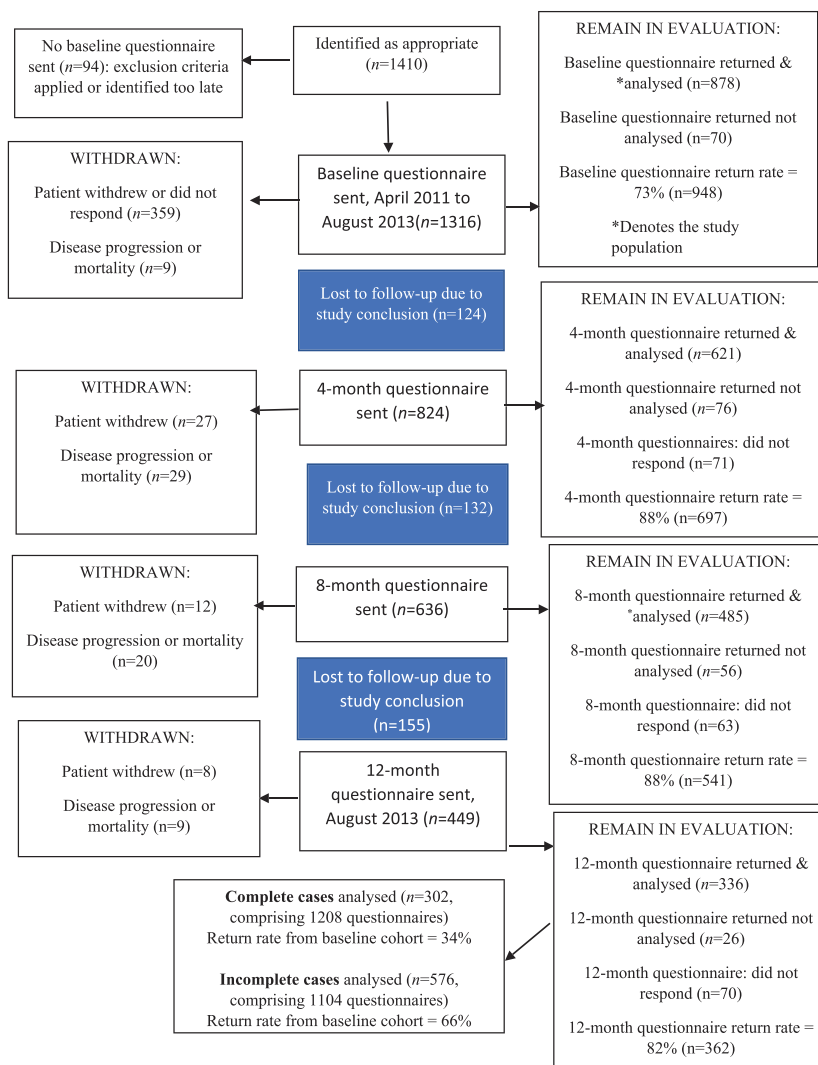
(Hodgkinson et al., 2007). In its original form, it comprises 35 items, but following Willems et al. (2015) and Amatya et al. (2014), the study focused on the 28 items in five domains relating to need. Following piloting with patients, the 28 items were reduced to 25. Domains, items and scoring are described in Table 1.

### 2.3 | Statistical analysis

Characteristics of patients were compared at T0 between the three cancer types and between those recruited in the two cohorts (pre and post the introduction of patient triggered follow-up). Participants at T2 were compared with non-responders. The total number of unmet needs (any strength) was aggregated (range 0–25; higher scores indicating more unmet needs) for each participant. Within each cancer type, unmet needs of any strength were aggregated by CaSUN domain, and domain totals were compared between tumour groups at T0. Individuals with

the highest levels of unmet needs were defined through inspection of the distribution of the number of unmet needs (any strength) in each tumour group. These highest need individuals were identified at T0 and T2 and compared with the remainder of respondents regarding baseline socio-demographic and clinical characteristics. Comparisons were conducted using tests appropriate to type of variable.

Responses from patients who had participated both at T0 and T2 were analysed to assess the changes to unmet needs (any strength) between T0 and T2. Four categories of unmet needs were identified: persistent (present at T0 and T2), emergent (not present at T0, present at T2), resolved (present at T0, not present at T2) and none (neither present at T0 nor T2). Numbers and percentages were tabulated for each item, for each tumour site. Changes in the total unmet needs from T0 to T2 were reported as means with 95% confidence intervals; changes within tumour sites were assessed (paired *t* test). Statistical significance was reported at the 5% level throughout.



#### Notes

Reasons for not analysing questionnaires: questionnaire completion was too early or late, although some of these could be included in the following time point.

Retention in relation to the baseline cohort (n = 878) 4 months: 70.7% (n = 621); 8 months: 55.2% (n = 485); 12 months: 38.3% (n = 336).

**FIGURE 1** Recruitment flow chart (April 2010 to August 2013) for all patients combined (breast, colorectal and testicular)

**TABLE 2** Baseline demographic and clinical characteristics of participants

	Breast N = 540	Colorectal N = 251	Testicular N = 87	
Participant demographics (Time T0 <sup>a</sup> )				
Age in years, mean (SD) <sup>b</sup>	61.2 (11.6)	72.0 (10.1)	39.1 (12.2)	
Ethnicity = White (n, %)	520 (97.6%)	241 (98.8%)	86 (98.9%)	
Domestic status = live with spouse/partner vs. live alone, live with others, or other (n, %)	368 (69.4%)	163 (67.9%)	56 (65.9%)	
Deprivation index mean (SD) [range: 1–32,482; 1 is highest]	21,550 (8046)	20,307 (9082)	19,888 (7668)	
Gender = female (n, %)	539 (99.8%)	101 (40.2%)	0 (0%)	
Highest education qualification (n, %)	No qualifications	81 (37.3%)	12 (14.0%)	
	GCSEs [age 16]	128 (25.7%)	33 (15.2%)	19 (22.1%)
	A-level [age 18]	34 (6.8%)	18 (8.3%)	8 (9.3%)
	Vocational qualification	133 (26.7%)	57 (26.3%)	27 (31.4%)
	University graduate	76 (15.2%)	28 (12.9%)	20 (23.3%)
Clinical				
Months, first diagnosis to T0, mean (SD)	6.61 (5.07)	6.83 (4.04)	5.17 (3.93)	
Months, end of last treatment to T0, mean (SD)	1.88 (1.47)	4.43 (2.41)	2.54 (1.73)	
Number of long-term conditions mean (SD)	0.80 (1.03)	1.00 (1.11)	0.25 (0.65)	
Treatments (n, %)				
Surgery only	45 (8.3%)	168 (66.9%)	13 (14.9%)	
Surgery + chemotherapy	7 (1.3%)	54 (21.5%)	70 (80.5%)	
Surgery + radiotherapy	26 (4.8%)	6 (2.4%)	3 (3.4%)	
Surgery + chemotherapy + radiotherapy	27 (5.0%)	22 (8.8%)	0 (0%)	
Surgery + hormone therapy	85 (15.7%)	0 (0%)	0 (0%)	
Surgery + radiotherapy + hormone therapy	216 (40.0%)	0 (0%)	0 (0%)	
Surgery + chemotherapy + radiotherapy + hormone therapy	71 (13.1%)	0 (0%)	0 (0%)	
Surgery + chemotherapy + radiotherapy + trastuzumab	34 (6.3%)	0 (0%)	0 (0%)	
Surgery + chemotherapy + hormone therapy + trastuzumab	28 (5.2%)	0 (0%)	0 (0%)	
Chemotherapy + hormone therapy + trastuzumab	1 (0.2%)	0 (0%)		
Chemotherapy only			1 (1.1%)	
Surgery + chemotherapy + microwave ablation	0 (0%)	1(0.4%)	0 (0.0%)	

<sup>a</sup>Completion of primary treatment (Baseline T0).

<sup>b</sup>Standard deviation.

### 3 | RESULTS

#### 3.1 | Baseline characteristics of participants

Of 1410 breast, colorectal and testicular patients screened for the study, 1316 were eligible and sent baseline questionnaire. Of these, 948 (72%) were returned, and 878 (66.7%) analysed. A detailed recruitment table is shown in Figure 1.

Baseline characteristics of participants are shown in Table 2. Amongst non-clinical features, testicular cancer survivors, as compared with colorectal and breast participants were more likely to have had higher education (Kruskal–Wallis test:  $p = 0.001$ ), were less likely to live alone (chi-squared test:  $p = 0.045$ ) and had fewer long standing illnesses (Kruskal–Wallis test:  $p < 0.001$ ). Chemotherapy was more common amongst testicular survivors (81.6%) (breast 31.1%, colorectal 30.7%) (chi-squared

test:  $p < 0.001$ ). Comparison of the characteristics of the two cohorts (pre and post the introduction of patient triggered follow-up) found no difference.

#### 3.2 | Unmet needs at T0

Amongst the 434 breast, 186 colorectal and 75 testicular cancer participants who completed all 25 CaSUN items, 56.2% (95% CI: 51.5% to 60.9%), 65.6% (95% CI: 58.7% to 72.5%) and 50.7% (95% CI: 39.1% to 62.2%), respectively, had no unmet needs at T0. The mean (SD) total number of unmet needs (any strength) at T0 was 2.74 (4.64) for breast, 1.71 (3.49) for colorectal and 2.01 (3.12) for testicular cancer. Most frequently reported unmet need for all tumour sites was fear of cancer recurrence (24.4% breast, 13.7% colorectal and 22.0% testicular) (Table 3).

**TABLE 3** Changes in weak/moderate/strong unmet needs between T0 and T2 ranked according to the proportion with weak/moderate/strong unmet needs at T2, by tumour site

CaSUN Domain <sup>a</sup>	Rank <sup>b</sup> T0	Rank <sup>c</sup> T2	CaSUN Need Description I need:	Unmet <sup>d</sup> needs at T0 n/(%)	Unmet <sup>e</sup> needs at T2 n/(%)	NN <sup>f</sup>	Resolved <sup>g</sup> unmet needs n (%)	Persistent <sup>h</sup> unmet needs n (%)	Emergent <sup>i</sup> unmet needs n (%)	No <sup>j</sup> unmet needs n (%)
<b>Breast (n = 312 returned survey at T0 and T2)</b>										
ES	1	1	Help to cope with my concerns that my cancer will recur	73 (24.4)	57 (18.9)	290	38 (13.1)	31 (10.7)	22 (7.6)	199 (68.6)
ES	3	2	Help to reduce the stress in my life	51 (16.9)	44 (14.6)	283	23 (7.8)	26 (8.9)	17 (5.8)	227 (77.5)
CCC	8	3	My doctors to talk to each other to coordinate my care	41 (13.7)	39 (13.2)	287	21 (7.3)	18 (6.3)	19 (6.6)	229 (79.8)
ES	11	4	Emotional support for me	38 (12.8)	38 (12.6)	289	20 (6.9)	14 (4.8)	23 (8.0)	232 (80.3)
COPING	2	5	Help to cope with others' expectations of me as a survivor	54 (17.8)	37 (12.3)	294	28 (9.5)	24 (8.2)	11 (3.7)	231 (78.6)
COPING	5	6	Help to move on with my life	47 (15.3)	34 (11.3)	297	21 (7.1)	21 (7.1)	11 (3.7)	244 (82.2)
ES	4	7	Help to adjust to changes to the way I feel about my body	47 (15.4)	34 (11.2)	299	24 (8.0)	21 (7.0)	12 (4.0)	242 (82.1)
COPING	6	8	Help to make decisions about my life in uncertain times	44 (14.5)	33 (10.9)	296	21 (7.1)	20 (6.8)	12 (4.1)	243 (82.1)
COPING	7	9	For others to acknowledge the impact of cancer on my life	43 (14.1)	33 (10.9)	297	21 (7.1)	19 (6.4)	10 (3.4)	247 (83.2)
COPING	10	10	Help to deal with my belief that nothing bad will happen again	39 (12.8)	33 (10.9)	297	14 (4.7)	22 (7.4)	8 (2.7)	253 (85.2)
COPING	9	11	Help to make my life count	39 (12.9)	33 (10.8)	298	15 (5.0)	23 (7.7)	9 (3.0)	251 (84.2)
CCC	20	12	My complaints regarding my care to be properly addressed	25 (8.3)	29 (9.8)	290	16 (5.5)	8 (2.8)	20 (6.9)	246 (84.8)
REL	14	13	Help to deal with problems with my sex life	34 (11.4)	26 (8.7)	292	16 (5.5)	16 (5.5)	8 (2.7)	252 (86.3)
REL	12	14	Help to deal with the impact of cancer on my relationships	35 (11.8)	24 (7.9)	292	22 (7.5)	13 (4.5)	10 (3.4)	247 (84.6)
CCC	16	15	Local health services that are available when I require them	31 (10.3)	23 (7.7)	290	20 (6.9)	10 (3.4)	12 (4.1)	248 (85.5)
CCC	15	16	To feel I can manage my health together with my health team	31 (10.4)	22 (7.4)	286	22 (7.7)	8 (2.8)	13 (4.5)	243 (85.0)

TABLE 3 (Continued)

CaSUN Domain <sup>a</sup>	Rank <sup>b</sup> T0	Rank <sup>c</sup> T2	CaSUN Need Description I need:	Unmet <sup>d</sup> needs at T0 n/(%)	Unmet <sup>e</sup> needs at T2 n/(%)	NN <sup>f</sup>	Resolved <sup>g</sup> unmet needs n (%)	Persistent <sup>h</sup> unmet needs n (%)	Emergent <sup>i</sup> unmet needs n (%)	No <sup>j</sup> unmet needs n (%)
CCC	19	17	The very best medical care	26 (8.7)	21 (7.1)	284	16 (5.6)	7 (2.5)	12 (4.2)	249 (87.7)
REL	13	18	Help to know how to support my family/partner	35 (11.7)	21 (7.0)	291	23 (7.9)	10 (3.4)	10 (3.4)	248 (85.2)
ES	17	19	To talk to other breast cancer survivors like me	31 (10.2)	19 (6.3)	289	21 (7.0)	8 (2.7)	10 (3.3)	260 (87.0)
INFO	18	20	Up to date information	28 (9.5)	17 (5.6)	287	21 (7.3)	6 (2.1)	9 (3.1)	251 (87.5)
INFO	21	21	Understandable information	22 (7.5)	16 (5.4)	286	17 (5.9)	4 (1.4)	9 (3.1)	256 (89.5)
COPING	24	22	Help with my spiritual beliefs	16 (5.2)	15 (4.9)	301	9 (3.0)	6 (2.0)	9 (3.0)	277 (92.0)
ES	22	23	Help to handle the topic of cancer in social/work situation	22 (7.2)	11 (3.6)	298	16 (5.4)	5 (1.7)	6 (2.0)	271 (90.9)
INFO	23	24	Information relevant for my partner/family	16 (5.4)	11 (3.6)	289	12 (4.2)	4 (1.4)	5 (1.7)	268 (92.7)
ES	25	25	Help to make new relationships	12 (3.9)	11 (3.6)	302	7 (2.3)	5 (1.7)	6 (2.0)	284 (94.0)
<b>Colorectal (n = 132 returned survey at T0 and T2)</b>										
CCC	3	1	Local health services available when I require them	14 (11.2)	13 (11.0)	113	7 (6.2)	4 (3.5)	9 (8.0)	93 (82.3)
ES	11	2	Help to reduce the stress in my life	10 (7.9)	12 (10.0)	116	4 (3.4)	3 (2.6)	9 (7.8)	100 (86.2)
CCC	15	3	The very best medical care	8 (6.6)	12 (9.8)	114	5 (4.4)	2 (1.8)	9 (7.9)	98 (86.0)
ES	1	4	Help to cope with my concerns that my cancer will recur	17 (13.7)	11 (9.2)	113	9 (8.0)	4 (3.5)	7 (6.2)	93 (82.3)
CCC	14	5	To feel I can manage my health together with my health team	9 (7.2)	11 (9.1)	114	5 (4.4)	1 (0.9)	10 (8.8)	98 (86.0)
CCC	6	6	My complaints regarding my care to be properly addressed	10 (8.3)	10 (8.3)	111	52 (1.8)	2 (1.8)	7 (6.3)	97 (87.4)
CCC	2	7	My doctors to talk to each other to coordinate my care	17 (13.6)	10 (8.2)	117	9 (7.7)	6 (5.1)	4 (3.4)	98 (83.8)
COPING	13	8	Help to make decisions about my life in uncertain times	10 (7.9)	9 (7.1)	122	4 (3.3)	5 (4.1)	4 (3.3)	109 (89.3)
REL	8	9	Help with problems with my sex life	10 (8.0)	9 (7.0)	121	4 (3.3)	6 (5.0)	3 (2.5)	108 (89.3)
INFO	7	10	Up to date information	10 (8.1)	8 (6.6)	118	6 (5.2)	3 (2.6)	5 (4.3)	101 (87.8)

(Continues)

TABLE 3 (Continued)

CaSUN Domain <sup>a</sup>	Rank <sup>b</sup> T0	Rank <sup>c</sup> T2	CaSUN Need Description I need:	Unmet <sup>d</sup> needs at T0 n/(%)	Unmet <sup>e</sup> needs at T2 n/(%)	NN <sup>f</sup>	Resolved <sup>g</sup> unmet needs n (%)	Persistent <sup>h</sup> unmet needs n (%)	Emergent <sup>i</sup> unmet needs n (%)	No <sup>j</sup> unmet needs n (%)
COPING	9	11	Help to deal with my belief that nothing bad will happen again	10 (8.0)	8 (6.3)	119	5 (4.2)	4 (3.4)	4 (3.4)	106 (89.1)
COPING	19	12	Help to make my life count	6 (4.8)	8 (6.3)	120	4 (3.3)	2 (1.7)	6 (5.0)	108 (90.0)
INFO	4	13	Understandable information	13 (10.5)	6 (5.0)	113	8 (7.1)	2 (1.8)	4 (3.5)	99 (89.6)
INFO	24	14	Information for family/others	4 (3.2)	6 (5.0)	115	2 (1.7)	2 (1.7)	4 (3.5)	107 (93.0)
ES	12	15	To talk to other colorectal survivors like me	10 (7.9)	6 (4.8)	119	6 (5.0)	3 (2.5)	3 (2.5)	107 (89.9)
ES	5	16	Emotional support for me	11 (8.7)	6 (4.8)	120	8 (6.7)	2 (1.7)	4 (3.3)	106 (88.3)
COPING	10	17	Help to cope with others' expectations of me as a survivor	10 (8.0)	6 (4.8)	119	4 (3.4)	5 (4.2)	1 (0.8)	109 (91.6)
COPING	21	18	Help to move on with my life	7 (5.6)	6 (4.8)	120	5 (4.1)	2 (1.7)	4 (3.3)	110 (92.5)
ES	18	19	Help to adjust to changes to the way I feel about my body	7 (5.6)	6 (4.7)	121	5 (4.1)	2 (1.7)	4 (3.3)	110 (90.9)
COPING	16	20	For others to acknowledge the impact of cancer on my life	8 (6.4)	5 (4.0)	117	2 (1.7)	4 (3.4)	1 (0.9)	110 (94.0)
REL	20	21	Help to know how to support my partner/family	6 (4.8)	5 (4.0)	120	4 (3.3)	2 (1.7)	3 (2.5)	111 (92.5)
ES	25	22	Help to make new relationships	4 (3.2)	5 (3.9)	121	2 (1.7)	2 (1.7)	3 (2.5)	114 (94.2)
REL	22	23	Help to deal with the impact of cancer on my relationships	5 (4.0)	4 (3.2)	122	3 (2.5)	2 (1.6)	2 (1.6)	115 (94.3)
COPING	23	24	Help with my spiritual beliefs	5 (4.0)	3 (2.4)	121	4 (3.3)	0 (0.0)	3 (2.5)	114 (94.2)
ES	16	25	Help to handle the topic of cancer in social/work situation	7 (5.6)	2 (1.6)	119	5 (4.2)	1 (0.8)	1 (0.8)	112 (94.1)
<b>Testicular (n = 41 returned survey at T0 and T2)</b>										
ES	1	1	Help to cope with my concerns that my cancer will recur	9 (22.0)	6 (14.6)	41	5 (12.2)	4 (9.8)	2 (4.9)	30 (73.2)
ES	2	2	Help to reduce stress in my life	6 (15.0)	5 (12.5)	39	4 (10.3)	2 (5.1)	3 (7.7)	30 (76.9)
REL	8	3	Help with problems with my sex life	4 (10.0)	4 (10.3)	39	4 (10.3)	0 (0.0)	4 (10.3)	31 (79.5)



TABLE 3 (Continued)

CaSUN Domain <sup>a</sup>	Rank <sup>b</sup> T0	Rank <sup>c</sup> T2	CaSUN Need Description I need:	Unmet <sup>d</sup> needs at T0 n/(%)	Unmet <sup>e</sup> needs at T2 n/(%)	NN <sup>f</sup>	Resolved <sup>g</sup> unmet needs n (%)	Persistent <sup>h</sup> unmet needs n (%)	Emergent <sup>i</sup> unmet needs n (%)	No <sup>j</sup> unmet needs n (%)
ES	10	4	To talk to other testicular cancer survivors like me	3 (7.5)	4 (10.0)	39	1 (2.6)	2 (5.1)	2 (5.1)	34 (87.2)
COPING	15	5	Help to move on with my life	3 (7.3)	4 (10.0)	40	2 (5.0)	1 (2.5)	3 (7.5)	34 (85.0)
COPING	17	6	For others to acknowledge the impact of cancer on my life	2 (5.1)	4 (10.0)	39	1 (2.6)	1 (2.6)	2 (5.1)	35 (89.7)
CCC	7	7	My doctors to talk to each other to coordinate my care	4 (10.0)	4 (9.8)	40	3 (75.0)	1 (2.5)	3 (7.5)	33 (87.5)
ES	9	8	Emotional support for me	4 (9.8)	4 (9.8)	41	3 (7.3)	1 (2.4)	3 (7.3)	34 (82.9)
COPING	4	9	Help to make decisions in uncertain times	6 (14.6)	3 (7.5)	40	4 (10.0)	2 (5.0)	1 (2.5)	33 (82.5)
ES	11	10	Help to adjust to changes to the way I feel about my body	3 (7.5)	3 (7.5)	40	2 (5.0)	1 (2.5)	2 (5.0)	33 (87.5)
CCC	16	11	The very best medical care	2 (5.1)	3 (7.5)	38	1 (2.6)	1 (2.6)	2 (5.3)	34 (89.5)
COPING	20	12	Help to make my life count	2 (4.9)	3 (7.5)	40	1 (2.5)	1 (2.5)	2 (5.0)	36 (90.0)
REL	13	13	Help to know how to support my partner/family	3 (7.3)	3 (7.3)	41	1 (2.4)	2 (4.9)	1 (2.4)	37 (90.2)
REL	14	14	Help to deal with the impact of cancer on my relationships	3 (7.3)	3 (7.3)	41	2 (4.9)	1 (2.4)	2 (4.9)	36 (87.8)
COPING	3	15	Help to cope with others' expectations of me as a survivor	6 (15.0)	2 (5.0)	40	5 (12.5)	1 (2.5)	1 (2.5)	33 (82.5)
COPING	5	16	Help to deal with beliefs that nothing bad will happen again	5 (12.2)	2 (5.0)	40	4 (10.0)	1 (2.5)	1 (2.5)	34 (85.0)
CCC	12	17	My complaints regarding my care to be properly addressed	3 (7.3)	2 (4.9)	41	2 (4.9)	1 (2.4)	1 (2.4)	37 (90.2)
INFO	22	18	Understandable information	1 (2.5)	2 (4.9)	40	1 (2.5)	0 (0.0)	2 (5.1)	37 (97.5)
CCC	18	19	Local health services available when I require them	2 (5.0)	1 (2.5)	40	1 (2.6)	1 (2.6)	0 (0.0)	37 (94.9)
ES	19	20	Help to handle the topic of cancer in social/work situations	2 (4.9)	1 (2.5)	40	1 (2.5)	1 (2.5)	0 (0.0)	38 (95.0)
ES	23	21	Help to make new relationships	1 (2.4)	1 (2.5)	40	1 (2.5)	0 (0.0)	1 (2.5)	38 (95.0)

(Continues)

TABLE 3 (Continued)

CaSUN Domain <sup>a</sup>	Rank <sup>b</sup> T0	Rank <sup>c</sup> T2	CaSUN Need Description	Unmet <sup>d</sup> needs at T0 n/(%)	Unmet <sup>e</sup> needs at T2 n/(%)	NN <sup>f</sup>	Resolved <sup>g</sup> unmet needs n (%)	Persistent <sup>h</sup> unmet needs n (%)	Emergent <sup>i</sup> unmet needs n (%)	No <sup>j</sup> unmet needs n (%)
CCC	6	22	To feel I can manage my health together with my health team	4 (10.0)	1 (2.4)	40	1 (2.5)	1 (2.5)	0 (0.0)	36 (90.0)
INFO	21	23	Up to date information	1 (2.5)	1 (2.4)	40	1 (2.5)	0 (0.0)	1 (2.5)	38 (95.0)
INFO	24	24	Information for family/others	0 (0.0)	1 (2.4)	39	0 (0.0)	0 (0.0)	1 (2.6)	38 (97.4)
COPING	25	25	Help with spiritual beliefs	0 (0.0)	0 (0.0)	40	0 (0.0)	0 (0.0)	0 (0.0)	40 (100.0)

<sup>a</sup>INFO = Information, CCC = Comprehensive cancer care, ES = Existential survivorship, REL = Relationships, COPING = Coping.

<sup>b</sup>Ranks of CaSUN items: Cancer Survivors Unmet Needs questionnaire at Time 0 (T0) post completion of all curative treatments.

<sup>c</sup>Ranks of CaSUN items at Time 2 (T2), 8 months after T0.

<sup>d</sup>Unmet needs at Time 0.

<sup>e</sup>Unmet needs at Time 2.

<sup>f</sup>Number of participants completing questionnaire at both T0 and T2.

<sup>g</sup>Unmet needs at T0 but not present at T2.

<sup>h</sup>Unmet needs present at T0 and at T2.

<sup>i</sup>Unmet needs absent at T0 and present at T2.

<sup>j</sup>Absence of unmet needs at both T0 and T2.

Breast and testicular participants experienced significantly higher unmet needs over colorectal in the Existential Survivorship and Coping domains (Kruskal-Wallis test:  $p = 0.010$ ,  $0.003$ , respectively); there was no statistically significant difference in unmet needs across the tumour sites in the Information, Comprehensive Cancer Care and Relationships domains. Item analysis revealed that fear of cancer recurrence and managing stress (both Existential Survivorship domain) and coping with others' expectations and decision making about the future (both Coping domain) contributed to the higher unmet needs of breast and testicular participants. A statistically significant (chi-square test:  $p = 0.012$ ) higher percentage of breast participants over colorectal and testicular experienced unmet need regarding adjustment to body changes (Existential Survivorship domain) (Table 3).

Inspection of the distribution by tumour group suggested that the number of unmet needs fell off sharply below the top decile. This high need group comprised (to the closest whole number) 52 (10.2%) breast, 28 (12.2%) colorectal and 10 (12.0%) testicular. These participants had at least 10, 7 and 7 different unmet needs, respectively. Breast cancer participants in the high needs group ( $\geq 10$  unmet needs), compared with the rest ( $< 10$ ), were significantly younger (mean [SD] 54.04 [10.11] vs. 61.55 [11.29] years; unpaired  $t$  test  $p < 0.0005$ ), more likely to have received chemotherapy ( $n = 27$ , 51.9% vs.  $n = 136$ , 29.6%; chi-square  $p = 0.001$ ) and tended to be more highly educated (Mann-Whitney  $U$  test  $p = 0.104$ ). Colorectal participants were also more likely to report high needs ( $\geq 7$  vs.  $< 7$ ) if they had received chemotherapy ( $n = 14$ , 50.0% vs.  $n = 60$ , 29.7%, chi-square  $p = 0.031$ ). No other background characteristics were significantly associated with reporting high numbers of needs for any tumour site.

### 3.3 | Participation and unmet needs at T2

Of the 540 breast, 251 colorectal and 87 testicular participants at T0, 312 (57.8%), 132 (52.6%) and 41 (47.1%), respectively, responded promptly at T2, a total of 485 (Figure 1). There were no significant differences between respondents and non-respondents on any baseline features, except amongst the colorectal patients where respondents reported a significantly higher level of education (data not shown).

Amongst the 249 breast, 103 colorectal and 38 testicular participants who completed all 25 CaSUN items at T2, 163 (65.5%, 95% CI: 59.5% to 71.4%) breast, 74 (71.8%, 95% CI: 63.0% to 80.7%) colorectal and 23 (60.5%, 95% CI: 44.2% to 76.8%) testicular had no unmet needs. The mean (SD) total number of unmet needs (any strength) at T2 was 2.18 (4.52) breast, 1.38 (3.65) colorectal and 1.76 (3.88) testicular. The most frequently reported item for breast and testicular participants remained fear of cancer recurring (18.9% and 14.6% respectively). For colorectal participants, availability of local health services was the most frequently reported item (11.0%), fear of recurrence being fourth (9.2%) (Table 3). The need to "reduce the stress in my life" was ranked in second place at T0 by participants from all three tumour sites.

Regarding individuals in the top decile for number of needs, 33 (11.0%) breast, 13 (10.8%) colorectal and 4 (10.0%) testicular were found to have at least 8, 5, and 7 unmet needs, respectively. High-needs breast cancer participants ( $\geq 8$ ), compared with the rest ( $< 8$ ), were significantly younger (mean [SD] 55.21 [9.20] vs. 61.07 [11.32] years, unpaired  $t$  test  $p = 0.002$ ) and (marginally) more likely to have received chemotherapy ( $n = 15$ , 45.5% vs.  $n = 79$ , 29.7%, chi-square test:  $p = 0.066$ ). Colorectal participants were also more likely to

report high unmet needs ( $\geq 5$  vs.  $< 5$ ) if they had received chemotherapy ( $n = 6$ , 46.2% vs.  $n = 28$ , 26.2%, chi-square test:  $p = 0.031$ ) and were more highly educated (Mann-Whitney  $U$  test  $p = 0.020$ ). No other background characteristics were significantly associated with high unmet needs for any tumour site.

Of the 52 breast cancer participants with the highest number of unmet needs at T0, 29 completed CaSUN at T2 of whom 16 (55.2%) remained in the top decile at T2. Similarly, 4/10 (40%) of colorectal and 2/4 (50%) testicular participants were in the highest decile at both T0 and T2.

### 3.4 | Changes in unmet needs between T0 and T2

For breast participants, there were statistically significant decreases in unmet needs in every domain between T0 and T2, except Comprehensive Cancer Care; Information ( $p = 0.029$ ), Existential Survivorship ( $p = 0.014$ ), Relationships ( $p = 0.013$ ) and Coping ( $p = 0.014$ ). There were no statistically significant changes in any domain for colorectal and testicular participants (Table 3). No statistically significant difference in changes (T0 to T2) were found for any domain in comparisons between tumour sites.

Item changes (T0 to T2) are shown in Table 3. Most participants reported no unmet needs at T0 and T2 (far right column). There is evidence that individuals' unmet needs change over time. For example, 38 breast cancer survivors reported fear of cancer was resolved at T2, whilst it had become a new issue for 22 others. However, changes in the relative importance of different needs between T0 and T2, as shown by the rankings, are mostly marginal. A need for doctors to talk more to each other and for emotional support moved up the breast cancer rankings to within the top five issues at T2. Similarly, for colorectal participants, health service availability, best medical care and shared decision making with the clinical team acquired increased importance at T2. Numbers in the testicular group were small but amongst those, help with sex life emerged as an unmet need.

## 4 | DISCUSSION

Understanding the nature and extent of unmet needs of cancer survivors, and how these change over time, and differ between tumour groups, is important to inform service planning and optimise care delivery. Consistent with findings of other studies (Armes et al., 2009; Boyes et al., 2012; Bredart et al., 2016; Valery et al., 2017; Willems et al., 2015), respondents reported low levels of unmet needs at both time points. Overall, levels of unmet need were lowest amongst colorectal survivors and diminished in all three groups over time (significantly for breast survivors). Others have also reported higher needs experienced by breast than colorectal survivors (Wylie et al., 2013) and falling levels of need by breast survivors (Minstrell et al., 2008; Von Heyman-Horan et al., 2013). Within these overall trends, there is evidence that for some individuals needs resolve and that new needs can emerge. Routine and regular monitoring of unmet needs using appropriate tools is

therefore necessary so that cancer care specialists and other health professionals can deliver personalised care based on individual needs, preferences and circumstances.

Fear of cancer returning was reported as the paramount unmet need throughout and has been reported as the most common unmet need in many other studies, including in breast, colorectal and mixed cancer populations (Amatya et al., 2014; Armes et al., 2009; Boyes et al., 2012; Simard et al., 2013; Valery et al., 2017). Testicular cancer survival rates are high (Cancer Research UK, 2017), but many men report persistent worries about recurrence (Bender et al., 2012; Smith et al., 2013, 2018). Receiving a diagnosis of a life-threatening disease at a relatively young age can cause long-term psychological distress (Schepisi et al., 2019).

Concern about care delivery was indicated by colorectal survivors, especially at T2. This finding aligns with other studies (Russell et al., 2015) but may reflect local services and not be generalisable. Research in other locations has noted more unmet needs associated with care delivery amongst breast than colorectal survivors (Wylie et al., 2013).

The need to reduce stress in life was the second most frequently cited need in all three tumour groups at T2. It was also in the top five unmet needs for breast and testicular survivors at T0 (11th for colorectal). Stress is also frequently cited as an unmet need in other studies (Brennan et al., 2016; Burris et al., 2015; Geller et al., 2014). Feelings of stress in life might arise from factors unrelated to cancer, but issues in early survivorship may provoke and exacerbate stress. In the transition from patient to survivor post-treatment, interactions with health care teams who have provided support diminish and assistance from friends and family may also fade as pressure mounts for the survivors to resume "normal" lives (Van Liew et al., 2014).

There is little comparative data available on testicular survivors (White et al., 2012; Willems et al., 2015), but existing evidence supports the findings of this study that existential issues, such as fear of recurrence and body image, are important (Bender et al., 2012; Smith et al., 2013). Problems with sexual functioning post-treatment was an emergent issue at T2 amongst testicular survivors, and a consistent source of concern to breast and colorectal survivors. This can be linked to body image changes, loss of confidence and problems restoring intimate relationships (Matheson et al., 2016).

### 4.1 | Implications for practice

A challenge for health services is to balance resource constraints with meeting the care needs of the rising cancer survivor population. Stratified clinical pathways as implemented within the British NHS (NHS Improvement, 2013) seek to target formal support on individuals with the highest needs, offering continuing outpatient appointments to selected survivors with health issues that are considered to warrant ongoing clinical follow-up. For other survivors, emotional and coping needs are addressed through supported self-management programmes which provide generic information and advice on keeping well and self-monitoring for signs of recurrence. In this study,

survivors with the highest number of unmet needs at T0 (and T2) reported at least 10 (and 8) breast, 7 (and 5) colorectal and 7 (and 7) testicular, suggesting significant negative impact on quality of life. About one half of people with the highest number of needs at T0 were also reporting the highest number of persistent needs at T2, the others at T2 reporting emerging needs. Other mixed cancer studies confirm that needs persist for many of the highest need survivors (Armes et al., 2009; Valery et al., 2017). These findings indicate that some survivors experience significant problems in the early months after treatment which can persist thereafter that warrant formal assessment and monitoring. This may also affect individuals discharged for self-care, as well as those receiving routine clinic follow up (Jefford et al., 2013).

In terms of targeting the survivors at risk of having high numbers of unmet needs, the findings of this study suggest that having had chemotherapy was significant amongst breast and colorectal survivors. Younger age was also important for the breast group. Higher education was associated with more unmet needs for colorectal survivors at T2 and marginally for breast survivors at T0. As an indicator of more challenging disease, chemotherapy may give rise to higher anxiety levels and result in a higher symptom burden extending into the post-treatment phase. No characteristics were associated with higher numbers of unmet needs amongst testicular survivors; however, the sample was small. Unlike chemotherapy, adjuvant hormone therapy was not associated with more unmet needs amongst breast survivors even though this is both a reminder of the diagnosis and a cause of side effects (Brennan et al., 2016).

Stress and coping issues are common in cancer survivors and can significantly affect wellbeing (Geller et al., 2014). Little is known about the value of routine clinic follow-up for meeting psycho-social needs, and views may vary between individuals. Contact with health professionals may provide reassurance to some that is foregone in self-management programmes. Alternatively, anticipation of hospital appointments may be an unwanted reminder of cancer for others. A recent study of men in the first 8 months after treatment for prostate cancer concluded that supported self-management was at least comparable (on various patient reported measures and unmet needs) to appointment-based follow-up and cost neutral (Frankland et al., 2019). Further in-depth analysis of expectations and experiences is, however, warranted, with tracking of recurrence, survival and adverse outcomes, as well as whole system costs, over a longer period (Frankland et al., 2019).

Fear of recurrence was found to be the most common unmet need and one that endures for all tumour groups. It is deemed “normal” amongst adults with a cancer history, and a degree of concern is considered functional to prompt self-protective responses and staying alert to signs of recurrence (Lebel et al., 2014). High or moderate levels of anxiety, however, can negatively affect quality of life and requires appropriate supportive care (Sarkar et al., 2015). Routine clinic contact enables anxieties to be identified and addressed. Health care teams can encourage disclosure, provide information and respond to psychosocial aspects of fear, including referral to local specialist resources if required. Some groups have been shown to

benefit from provision of a survivor care plan and a written summary for self-management (Brennan et al., 2014; Howell et al., 2017; Jefford et al., 2017). Mind-body interventions (such as cognitive-behavioural and mindfulness) have also been found efficacious (Hall et al., 2018) and targeted on line self-management interventions such as ConquerFear (Butow et al., 2017; Smith et al., 2017), and Mini-AFTERc (Davidson et al., 2018) can be integrated into specialist nurse clinical practice. Follow-up has also been reported beneficial for providing sexual function information and discussing relationship issues (Averyt & Nishimoto, 2014; Brand et al., 2015) identified as significant needs for some survivors in this study, with implications for wellbeing and quality of life.

Contrary to other evidence reporting declining need for emotional support over time amongst breast cancer survivors (Burriss et al., 2015), this study identified existential survivorship was a continuing issue. Social support from family and friends is beneficial to the psychological wellbeing of survivors (Smith et al., 2018), and decreasing levels of social support after treatment have been linked to reduced quality of life (Grimmett et al., 2017). Assessment of gaps in support through follow-up, when survivors are searching for meaning in their life, is relevant for all cancer survivors to instigate signposting to support groups, or health and well-being programmes, or referral to targeted professional input (Fenlon et al., 2015; Grimmett et al., 2017).

Table 3 provides extensive information on observed change rates in 25 different unmet needs for all three tumour groups, enabling required sample sizes to be formulated for future studies seeking to evaluate targeted interventions for specific needs.

## 5 | LIMITATIONS

There are several limitations to this study. The CaSUN survey instrument was modified following patient feedback, but the changes were minor and did not affect the scoring which followed recommended guidelines. Indeed, demonstrates that the five domains behaved similarly across the three tumour sites confirming that the modified tool performed consistently. The testicular sample was small and the study ran out of time and resources such that some participants were not included in the follow-up data collection thereby reducing the size of the sample in all three tumour groups at T2. Moreover, follow-up was limited to 8 months whilst survivorship is lifelong. Questionnaire responses included information on needs that were met (80% of all reported needs), and these have not been reported. Unmet needs of all strengths were combined in the analysis without any weighting. The study was conducted in one health trust in England, and findings may not be generalisable. The study combined patients treated over a period in which follow-up protocols were changing and by the end of the study 24% of participants were in self-management follow up regimens. Comparison of the two groups, however, found no difference at T0 nor in the subsequent change in number of unmet needs from T0 at T2.

## 6 | CONCLUSIONS

This study contributes to the knowledge regarding unmet supportive care needs of breast, colorectal and testicular cancer survivors early after the end of treatment and two thirds of the way through their first year. The results indicate that most survivors had few or no unmet needs at the end of treatment or 8 months later but a small proportion had significant numbers of persisting or emerging needs. Further research is required to explore the long term clinical, psychosocial and economic implications of supported self-management programmes, compared to clinic follow-up for different groups of cancer survivors. Individual survivors have varying levels and types of needs and personalised approaches to care are required. A recent analysis found that individuals' background and presence of symptoms play a more important role in the profile of unmet needs than cancer type (Watanabe et al., 2020). Our study findings differ from those of others in some respects but inconsistencies in evidence about unmet needs have been widely reported (Puts et al., 2012; Willems et al., 2015). The reasons for this also require investigation, including the extent to which the differences reflect local factors and settings.

### AUTHOR CONTRIBUTIONS

LB and JC secured the funding contribution provided by the National Cancer Survivorship Initiative (NCSI) and Macmillan Cancer Support. LB, ND and PW refined and tested the modified unmet needs questionnaire measurement tool (Cancer Survivors Unmet Needs questionnaire) following a pilot study. Clinical and subject expert advice was provided by Peter Simmonds, Jane Winter, Lynn Dodson (LD), Andy Turner, AR and Jessica Corner (JC). Richard Wagland, KP, Elizabeth Lawson and LB contributed to data collection and data entry. PW, HG, LB and AR drew up the plan for analysis and PW, and HG, carried out the statistical analysis of unmet needs, with support from KP for data cleaning. Lynn Batehup (LB), Heather Gage (HG) and Peter Williams (PW) drafted the paper, with detailed review on drafts by Nicola Davies (ND), Katerina Porter (KP) and Alison Richardson (AR). All authors reviewed and commented on the paper prior to submission.

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### CONFLICT OF INTEREST

The authors declare they have no conflict of interest.

### DISCLAIMER

The views expressed in this article are those of the author(s) and not necessarily those of the National Health Service (NHS), the National Institute of Health Research (NIHR), the Department of Health and Social Care (England) or Macmillan Cancer Support.

### DATA AVAILABILITY STATEMENT

Data available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

### ORCID

Lynn Batehup  <https://orcid.org/0000-0002-9553-6777>

Richard Wagland  <https://orcid.org/0000-0003-1825-7587>

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