

# The holistic management of consequences of cancer treatment by a gastrointestinal and nutrition team: a financially viable approach to an enormous problem?

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## ABSTRACT

There is no national NHS tariff to fund services for patients experiencing long-term bowel and nutritional problems after cancer treatment. In this paper, we report the clinical characteristics and outcomes of patients referred to our service and the estimated cost of a completed episode of care. Patient characteristics, symptom severity, investigations, diagnoses, number of clinic visits and referrals elsewhere were recorded in a prospective cohort study. During 2013–14, 325 patients completed assessment and treatment. The majority of original cancer diagnoses were urological (43%) and gynaecological (21%). A median of six investigations were requested. 62% were found to have three or more new diagnoses including small intestinal bacterial overgrowth (46%), vitamin D deficiency (38%), bile acid malabsorption (28%), gastritis (22%), radiation-induced bleeding (20%), vitamin B12 deficiency (17%), pelvic floor weakness (17%), colorectal polyps (13%) and pancreatic insufficiency (5%). A median of three visits were required and all commonly reported gastrointestinal symptoms improved by discharge. The mean episode of care per patient was costed at £1,563. Effective amelioration of chronic gastrointestinal toxicity after cancer treatment costs substantially less than treating the cancer in the first place and requires an NHS tariff.

**KEYWORDS:** Cancer, cancer treatment, cost, radiotherapy, chemotherapy, surgery, hormone treatment, gastrointestinal, consequences, symptoms, survivorship

## Introduction

The GI [gastrointestinal] and Nutrition Team (GIANT) service is based at the Royal Marsden NHS Foundation Trust, a specialist tertiary centre for cancer treatment that has an open-access policy accepting referrals. The GIANT service provides comprehensive care for patients experiencing chronic GI symptoms and/or nutritional issues after completion of their cancer treatment.

Long-term changes in bowel function after cancer treatment are common<sup>1</sup> and can have a devastating effect on the daily activity and quality of life of people living with and beyond cancer. It is clear that as many as 80% of patients develop a chronic change in their bowel function after pelvic radiotherapy, and this change affects quality of life in up to half of all treated patients. However, the incidence and prevalence after surgery, chemotherapy or biological therapy is less well researched. Recent clinical trials suggest that grade 3 or 4 toxicity is reported to occur with a frequency of 5–47% in patients receiving chemotherapy or biological agents, and a larger proportion required dose reduction for lesser but still troublesome toxicity.<sup>2</sup> After GI surgery, long-term toxicity is also highly prevalent, although most studies rely on physician-rated scoring, which is known to underestimate the degree of bother compared with patient-reported outcome measures.

Change in GI function occurs as a result of alteration in GI physiological function.<sup>3</sup> Depending on which GI functions are altered, a variety of symptom profiles can present.<sup>4</sup> An algorithmic approach to the assessment, investigation and management of GI symptoms in our clinic has been adopted by the multidisciplinary team. This systematic approach generates evidence of contributing causes before recommending management options. The GIANT service started in 2000, and was delivered single-handedly by a consultant gastroenterologist. A collaborative approach was set up with the consultant dietitian in 2006 to manage people experiencing a chronic change in their bowel function after treatment with pelvic radiotherapy for cancer. In 2011, the service was awarded additional funding by Macmillan Cancer Support to appoint a nurse consultant and an additional specialist dietitian.

In addition to managing GI and nutritional issues, the team offer a holistic needs assessment (HNA) to all patients newly

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referred to the service.<sup>5</sup> The team liaises closely with a number of other services, both in the hospital and in the primary care setting, such as psychological support services, physiotherapy, pain services and information services, and refers to existing services – particularly biofeedback, erectile dysfunction, psychosexual counselling, urology, endocrinology and dermatology clinics.

The GIANT service has capacity of 1,200 outpatient slots annually and receives about 400 new referrals per year for patients who require specialist assessment in the clinic. In recent years, demand has increasingly outstripped capacity. In view of this demand, it has become increasingly pressing to be absolutely clear about the demographics of our population, the type of problems they present with, the nature of the investigations, the management they require and the benefits of the service we provide. Because there is no tariff payable for GI consequences of cancer treatment, we also wished to provide data that might help commissioners to identify the individual patient cost for an episode of care.

## Methods

This prospective study was approved by the hospital's Research and Development Committee (Service Evaluation 36). Consent from patients was not required. Details for all patients attending the GIANT service were collected. This analysis included patient characteristics, the number of investigations requested, new diagnoses, referrals to other services and the number of clinic appointments before discharge. All patients underwent a full assessment of their GI symptoms and were routinely asked to indicate on a Bristol Stool Chart<sup>6</sup> what types of stool they were experiencing and the frequency of their bowel movements. Additionally, all patients completed a modified Gastrointestinal Symptom Rating Scale (GSRS) questionnaire at each clinic visit, which is routinely used to aid clinical management. The GSRS has been previously validated for use in those with gastro-oesophageal reflux disease, peptic ulcer disease, those who have undergone GI surgery (eg pancreatectomy), coeliac disease, chronic intestinal pseudo-obstruction, chronic non-specific abdominal complaints and irritable bowel syndrome.<sup>7–13</sup> In addition, at each clinic visit patients were asked to score on a visual analogue scale (VAS) general quality of life (QoL) as they perceived it (0 = worst possible QoL, 10 = best possible QoL) and the impact their bowel symptoms had on their quality of life (0 = no impact on QoL, 10 = severe impact on QoL).

All patients who had any abnormal gastrointestinal symptoms were investigated and treated systematically using our peer-reviewed investigational algorithm.<sup>14</sup> They were discharged from our clinic when the clinician and the patient agreed that further appointments were not necessary – usually when bowel function had been optimised or there were no further treatments to offer the patient. Here, we report a consecutive cohort of patients discharged from our service over a 1-year period.

Because this was a prospective workload analysis, no sample size calculation was required. Previous retrospective data indicated that around 300 patients were discharged from the service in the previous year. This allowed statistical analysis with descriptive statistics and non-parametric tests, including the Wilcoxon Rank test, sign test and  $X^2$  test to test for statistically significant differences in the observations of those treated with pelvic radiotherapy versus those who received

other cancer treatment modalities and at different time points (ie first consultation versus time of discharge from the service).

The mean cost per completed episode of care by the GIANT service was calculated using the percentage of investigations requested, diagnoses made, prescriptions issued, the number of times seen in clinic and whether dietetic input was required on the basis of the 2013–14 NHS tariff<sup>15</sup> for investigations (multiplied by 1.2 to include the Market Forces Factor (MFF) for an inner London specialist cancer centre), the 2013–2014 prices for medications stated in the *British National Formulary*<sup>16</sup> and additional financial data from the finance team.

## Results

### Demographics

We report data collected for a year – April 2013 to March 2014 – during which time 326 patients were discharged from the GIANT service. One patient was excluded from this analysis because they did not have a cancer diagnosis. During that year, there were 1266 face-to-face patient contacts, of which 398 were new patients and 868 follow-up consultations. The majority of referrals (62%) originated from oncology teams in our institution. 24% were referred from other secondary or tertiary care units and 14% were GP-instigated referrals. Slightly more men (56%) than women were referred (Table 1).

Modern cancer treatments are often multimodal. Full details of previous treatments are frequently not available. However, 68% of people referred received pelvic radiotherapy as part of their treatment. An additional 5% of people had received whole-body irradiation. The others had been treated with surgery, chemotherapy and biological therapies, either alone or in combination.

Symptom profiles confirmed multiple troublesome GI symptoms for 82% of people. Patients who could be managed with endoscopic assessment alone, without any other tests because their only symptom was rectal bleeding, numbered only 4%.

Almost all (95%) of the people referred to the GIANT service were offered a HNA at their first appointment. 41% opted not to complete the HNA; 59% (n = 192) completed the form. The concerns thermometer is a VAS denoting the amount of distress a person has experienced acutely in the past week with 0 meaning no distress and 10 meaning extreme distress. Guidelines state that a score of 5 or above in a district general hospital should trigger a referral for psychological support. In a specialist cancer centre, a score of 7 or above would warrant referral for additional psychological support. In our patient group, 35% scored 7 or higher. On questioning further, this was mainly due to the impact of their bowel symptoms, ie episodes of incontinence, and for most people, this resolved as contributing factors were identified and long-term management was established. The demographic profile of those who completed the questionnaires did not differ significantly from that of the entire cohort. Table 2 describes the most prevalent non-physical concerns identified. Fig 1 shows the physical concerns highlighted by patients.

After systematic clinical assessment, in accordance with our algorithmic approach,<sup>12</sup> the following investigations were requested: blood tests (86%), oesophago-gastro-duodenoscopy ± biopsies (60%) + duodenal aspirate (58%), glucose hydrogen methane breath test (53%), 23-seleno-25-homo-tauro-cholic acid scan (51%), flexible sigmoidoscopy (48%), stool sample for

**Table 1. Characteristics of the entire patient cohort discharged from our clinic over one year and divided into subgroups.** The differences in age, gender, time from cancer diagnosis to referral to the GIANT service and body mass index were compared between patients treated with pelvic radiotherapy and those treated with other cancer treatment modalities using the sign test.

Characteristics	Clinic population (n = 325)	Treated with pelvic radiotherapy (n = 220)	Treated with other treatment modalities (n = 105)	Sign test, p
Age (years), median (range)	68 (20–90)	68 (21–90)	65 (20–85)	<0.001
<b>Gender</b>				0.001
Male	183 (56)	139 (63)	45 (43)	–
Female	142 (44)	81 (37)	60 (57)	–
Years from diagnosis to referral to GIANT, median (range)	3.4 (0.1–42.2)	3.6 (0.2–38.7)	2.0 (0.1–42.2)	0.001
Body mass index, median (range)	25.1 (14.4–47.8)	24.1 (15.7–47.8)	26.2 (14.4–47)	<0.001
Urological cancer	143 (44)	126 (57)	17 (16)	N/A
Prostate cancer	128 (98)	120 (95)	8 (47)	
Gynaecological cancer	67 (21)	57 (26)	10 (10)	N/A
Cervical cancer	28 (42)	28 (49)	0 (0)	
Colorectal cancer	37 (11)	29 (13)	8 (8)	N/A
Rectal cancer	22 (59)	17 (59)	5 (63)	
Upper gastrointestinal cancer	34 (10)	3 (1)	31 (29)	N/A
Gastric cancer	11 (32)	0 (0)	11 (35)	
Head and neck cancer	5 (2)	0 (0)	5 (5)	N/A
Thyroid cancer	4 (80)	0 (0)	4 (80)	
Haematology	23 (7)	2 (1)	21 (20)	N/A
Multiple myeloma	5 (22)	0 (0)	5 (24)	
Other cancer diagnoses	16 (5)	3 (1)	13 (12)	N/A
Breast cancer	7 (44)	1 (33)	6 (46)	

Data are n (%) unless otherwise specified. GIANT = GI [gastrointestinal] and Nutrition Team; N/A = not applicable.

**Table 2. Holistic needs identified at initial assessment and concerns thermometer scores.**

Holistic needs	Prevalence of holistic needs, n (%) (n = 192)	Concerns thermometer scores	Frequency of score, n (%) (n = 192)
Worry, anxiety and fear	96 (50)	0	31 (16)
Memory and concentration problems	81 (42)	1	14 (7)
Problems making plans	69 (36)	2	12 (6)
Anger or feelings of guilt	66 (34)	3	18 (9)
Sadness and depression	63 (33)	4	9 (5)
Sexual concerns	61 (32)	5	9 (5)
Housing or financial concerns	53 (28)	6	16 (8)
Caring responsibilities	44 (23)	7	27 (14)
Concerns about relationships with others	38 (20)	8	23 (12)
Loneliness and isolation	36 (19)	9	12 (6)
Loss of meaning or purpose in life	29 (15)	10	5 (3)
Regrets about the past	29 (15)	Missing score	16 (8)
Feelings of hopelessness	29 (15)		

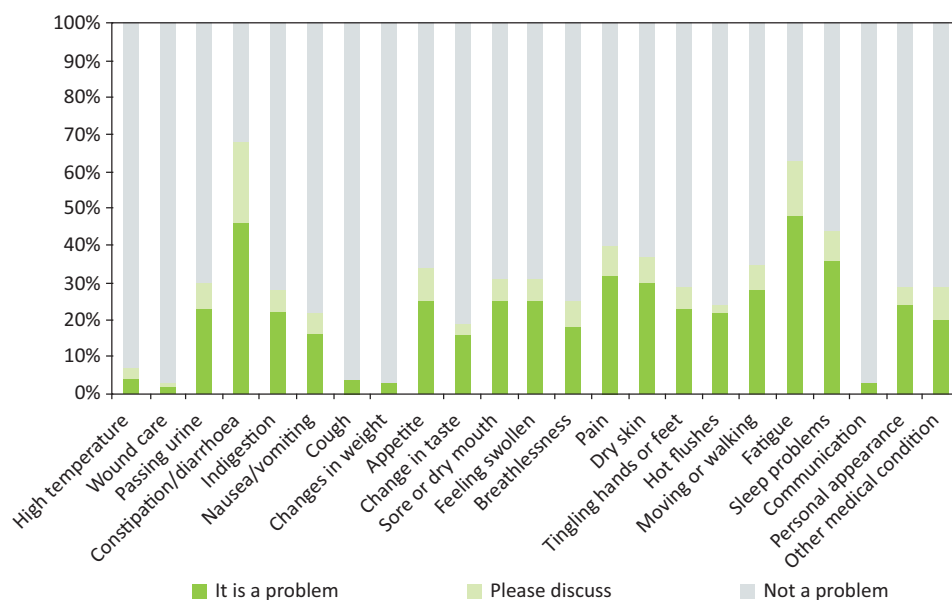


Fig 1. Physical concerns highlighted by holistic needs assessment analysis (n = 192).

faecal elastase (45%), colonoscopy (20%), other radiological imaging (3%).

People underwent a median of 6 investigations (range 0–10). The diagnoses made confirmed the complexity of the factors contributing to people's symptom profiles (Table 3). The median number of new GI diagnoses made per person was 3 (range 0–9).

**Table 3. The most prevalent new gastrointestinal and nutritional diagnoses made in the GIANT clinic.**

Diagnosis	Prevalence, n (%)
	(n = 325)
Small intestinal bacterial overgrowth	151 (46)
Vitamin D deficiency	124 (38)
Bile acid malabsorption	90 (28)
Gastritis	72 (22)
Radiation-induced telangiectasia resulting in rectal bleeding	65 (20)
Vitamin B12 deficiency	55 (17)
Weak pelvic floor musculature	55 (17)
Gastrointestinal polyp requiring polypectomy	43 (13)
Trace element deficiency	37 (11)
Hiatus hernia	35 (11)
Diverticular disease	34 (10)
Excessive dietary fibre intake	30 (9)
Oesophagitis	23 (7)
Iron deficiency anaemia	22 (7)
Pancreatic insufficiency	16 (5)
Faecal loading	16 (5)
Induced by proton pump inhibitor	16 (5)

Data are n (%). GIANT = gastrointestinal and nutrition team.

Only 18% of people had a single cause for their symptoms. Over 62% of people had more than three contributing causes.

People were seen a median of three times in our clinic (1–16) before being discharged from the GIANT service. A fifth of people (21%) did not need to be seen again after their initial consultation. People requiring more than 1 visit (n = 256) remained under our care for a median of 6 months (range 0.4–141.7).

During this year, 16% of patients were re-referred to the service having been seen previously and discharged. People re-referred after discharge were significantly older (median 72 years, range 42–87) than those who were referred for the first time (67.5 years, 20–90) (p=0.003). Tertiary treatment centres made more re-referrals (25%) than initial, new referrals (19%) to our team (p=0.012).

The team requested more tests for those newly referred to the service (median 7, range 0–10) than for those who were referred back (4, 0–9; p=0.007). Those referred back were diagnosed with a median of two new contributing GI diagnoses (0–7), whereas newly referred patients were diagnosed with a median of three (0–9; p=0.002). None of the symptom profiles were statistically different for either group. There were no differences in terms of contributing cause identified in the two groups.

Of referrals from the GIANT clinic to other teams, 36% of people required specialist dietetic interventions as part of their management plan. Other referrals included those to the psychological support team (5%), urology team (3%), endocrinology team (2%), physiotherapy team (1%), psychosexual counseling team (1%), biofeedback team (1%) and pain team (1%).

#### Treatment with pelvic radiotherapy versus other cancer treatments

The referral base initially was almost exclusively patients with GI symptoms after radiotherapy to a cancer in the pelvis. Over time, the number of patients receiving other treatments has increased. There were no statistically significant differences in

**Table 4. Difference in prevalence of symptoms as measured on the GSRS for all patients at first consultation and at time of discharge from the GIANT service.**

	All patients, n (%) (n = 325)		Wilcoxon signed-rank test
	First consultation	Discharge	
<b>Abdominal pain</b>			<0.001
None	107 (33)	119 (37)	
Mild	115 (35)	133 (41)	
Moderate	79 (24)	54 (17)	
Severe	24 (7)	19 (6)	
<b>Bloating</b>			0.03
None	118 (36)	119 (37)	
Mild	110 (34)	132 (41)	
Moderate	77 (24)	57 (18)	
Severe	20 (6)	17 (5)	
<b>Heartburn</b>			0.86
None	178 (55)	167 (51)	
Mild	99 (30)	120 (37)	
Moderate	38 (12)	32 (10)	
Severe	10 (3)	6 (2)	
<b>Reduced appetite</b>			0.23
None	214 (66)	211 (65)	
Mild	65 (20)	76 (2)	
Moderate	26 (8)	23 (7)	
Severe	20 (6)	15 (5)	
<b>Nausea</b>			0.36
None	196 (60)	198 (61)	
Mild	86 (26)	90 (28)	
Moderate	33 (10)	31 (9)	
Severe	10 (3)	6 (2)	
<b>Vomiting</b>			0.03
None	234 (72)	245 (75)	
Mild	58 (18)	56 (17)	
Moderate	24 (7)	18 (6)	
Severe	9 (3)	6 (2)	
<b>Urgency</b>			<0.001
None	46 (14)	46 (14)	
Mild	91 (28)	146 (45)	
Moderate	130 (40)	96 (30)	
Severe	58 (18)	37 (11)	
<b>Faecal leakage</b>			<0.001
None	108 (33)	132 (41)	
Mild	115 (35)	128 (39)	
Moderate	55 (17)	39 (12)	
Severe	47 (14)	26 (8)	
<b>Rectal bleeding</b>			0.11
None	188 (58)	191 (59)	
Mild	92 (28)	104 (32)	
Moderate	36 (11)	20 (6)	
Severe	9 (3)	10 (3)	
<b>Sexual concerns</b>			0.04
None	220 (68)	226 (70)	
Mild	31 (10)	37 (11)	
Moderate	35 (11)	28 (9)	
Severe	39 (12)	34 (10)	

Differences were compared with the Wilcoxon signed-rank test. GIANT = gastrointestinal and nutrition team; GSRS = Gastrointestinal Symptom Rating Scale.

terms of gender, the number of tests requested by the team, the total number of GI diagnoses made, the number of visits to the service before discharge, the number of people who completed a HNA, or the number of referrals to other teams between the group treated with pelvic radiotherapy and that given other treatment modalities.

### Change in symptoms between referral and discharge

At the time of the initial consultation, 93% had one or more moderate or severe symptoms (median 5, range 1–18). Table 4 describes and compares the change in symptoms at the initial consultation and at discharge. General QoL improved from a median of 2 (range 0–6) out of 10 at the initial consultation to a median of 6 (3–7) on the VAS score at discharge ( $p \leq 0.001$ ). The effect that bowel symptoms could have on the general QoL was measured on a VAS scale, with 0 denoting no impact at all and 10 implying a severe impact. The impact that residual bowel symptoms continued to have on QoL worsened from a median of 1 (0–6) to a median of 4 (2–7) at discharge ( $p \leq 0.001$ ).

### Cost implications

Initial outpatient consultation cost £192, investigations £732 (with related prescription costs of £137), follow-up £250, specialist dietetic input £66 and prescription costs for treatment £186, amounting to an average cost of £1,563 per patient.

## Discussion

This prospective study shows that the GIANT service improves the outcomes for people living with and beyond cancer in terms of GI symptom burden, impact on daily activity and QoL, and that this costs substantially less than the original cost of treatment for cancer, which causes the symptoms in the first place. Additionally, the costs are substantially less than those for patients with chronic GI disorders unrelated to cancer but experiencing very similar symptoms to those seen in our patient cohort. The benefits demonstrated from our interventions can be achieved with very few appointments for the average patient.

There is currently no national NHS tariff for the provision of a service dealing with GI consequences of cancer treatment. In addition, there is very little research documenting the financial burden of these consequences of treatment to the patient, their family, healthcare services or society at large.

Our data provide the first figures for an episode of care for a patient with GI consequences of cancer treatment. The model used does not include overhead costs such as administrative support, clinic space, laboratory staff costs and multidisciplinary meeting preparation costs, but does include the salary costs for a consultant gastroenterologist, a nurse consultant and a specialist dietitian.

Annual NHS costs for cancer services are £5 billion, but the cost to society as a whole – including loss of productivity – is £18.3 billion.<sup>17</sup> The NHS tariff for cancer treatments that patients attending the GIANT service commonly received lies between £2,000 and £45,000 (Table 5). These are acute treatment tariffs and they do not reflect the complexity of multimodal cancer treatment. They also do not include further payments for investigating the patient to reach the original cancer diagnosis, follow-up or investigating and treating relapse.

**Table 5. Examples of the NHS tariffs for the cancer treatments commonly given to patients attending the GIANT service.** Tariffs vary to a small degree with changes in the exact treatment regimen.

Cancer treatment	NHS tariff, £
<b>Prostate cancer</b>	
Radiotherapy (depending on type)	6,000–9,000
<b>Gynaecological cancer</b>	
Long course radiation with concomitant chemotherapy (carboplatin plus paclitaxel)	14,800
<b>Oesophageal or gastric cancer</b>	
Surgery	10,500
Additional chemotherapy	2,000–6,000
<b>Pancreatic cancer</b>	
Whipple's procedure plus adjuvant radiation with concomitant chemotherapy (epirubicin, cisplatin and capecitabine)	15,900
<b>Colon cancer</b>	
Right hemicolectomy plus adjuvant capecitabine	8,300
<b>Rectal cancer</b>	
Anterior resection	10,800
Long-course radiation with concomitant chemotherapy (capecitabine and oxaliplatin) followed by anterior resection, followed by adjuvant chemotherapy (capecitabine)	45,000

GIANT = gastrointestinal and nutrition team.

The cost of managing GI consequences of cancer treatment can also be compared to the cost of treating other GI disorders not associated with malignancy. The best data lie with patients diagnosed with inflammatory bowel disease who can have symptoms very similar to those of people with GI consequences of cancer treatment. The annual cost of care is estimated to be £1,693 for patients with ulcerative colitis in remission, £10,760 for those with active ulcerative colitis, £1,799 for Crohn's disease in remission, and £10,513 for active Crohn's disease.<sup>18</sup>

As the cost of specialist assessment and treatment of GI consequences of cancer therapies is so much less than the cost of treating the cancer, it is unclear why it has proven so difficult to persuade commissioners to consider specialist services to manage these issues. Further detailed economic analysis is required as a matter of urgency to inform commissioners because there are large numbers of patients.

Because referrals to our clinic are substantially outstripping capacity, we judge it important to discharge patients to the care of their GP and oncology teams as quickly as possible. A re-referral rate of 16% could indicate a number of problems arising as a result of this policy. Firstly, our initial assessment of patients might sometimes be inadequately comprehensive, and on occasion we might be failing to follow our own algorithm sufficiently carefully. Secondly, it could suggest that GI symptoms after cancer treatment change over time, especially

because no difference could be identified in the number and types of diagnoses made between patients seen once and those re-referred. Thirdly, some patients could have a level of anxiety from residual symptoms that requires intermittent reassurance. Finally, the re-referral rate could suggest that some patients require additional support to make and maintain the complex lifestyle changes that optimise their bowel function. We are developing new strategies to try and reduce this re-referral rate, especially because patients who were re-referred to the team required significantly fewer investigations. This finding could indicate a reliance on previous investigations done but also highlights the importance of a comprehensive long-term management plan at discharge that patients, carers and healthcare professionals all understand.

The results from completed HNAs showed that patients are concerned not only regarding physical symptoms but also about a whole range of practical, emotional and spiritual matters. This analysis also shows that overall QoL improves at the time of discharge from our service but the impact that residual bowel symptoms continue to have on QoL worsens. This could be because of increased awareness of management of bowel symptoms by patients themselves and the need for motivational strategies to encourage ownership of these management strategies to maintain them long term.

The Royal Marsden Hospital's innovative GIANT clinic predated the aims outlined in the National Cancer Survivorship Initiative vision<sup>19</sup> and in the subsequent *Improving outcomes: a strategy for cancer*,<sup>20</sup> which included tailored support for people living with consequences of cancer treatment. This service also supports the vision expressed in *Living with and beyond cancer: taking action to improve outcomes*,<sup>21</sup> which was designed to support commissioners, providers and others to take the actions necessary to drive improved survivorship outcomes. Additionally, it advocates for the need for a small number of supraregional specialist centres, which would deliver and coordinate care for patients with severe, complex pelvic problems and be a focus for education and research.

There is currently a paucity of literature describing demographic details, symptom severity and burden of people living with and beyond cancer who experience chronic changes in their bowel function and what investigations they require to identify contributing organic causes. Although our institution is a specialist tertiary referral centre, most of the patients described in this study came from our local population. However, our observations reflect the needs of those in all cancer centres. A major challenge for the future of cancer service provision is to develop accessible and appropriate supportive care because there is no doubt that the scale of unmet need is substantial and that systematic assessment and treatment improves symptoms. ■

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