### ORIGINAL ARTICLE

# Gastrointestinal symptoms after pelvic radiotherapy: a national survey of gastroenterologists

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#### **Abstract**

Purpose Seventeen thousand patients receive treatment with radical pelvic radiotherapy annually in the UK. Up to 50% develop significant gastrointestinal symptoms. The National Cancer Survivorship Initiative has identified access to specialist medical care for those with complications after cancer as one of their four key needs. We aimed to determine the current practice of British gastroenterologists with regards to chronic gastrointestinal symptoms after pelvic radiotherapy.

Methods A questionnaire was developed and sent up to a maximum of five times to all UK consultant gastroenterologists.

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R. P. Symonds Department of Clinical Oncology, Leicester Royal Infirmary, Leicester, UK Results Eight hundred sixty-six gastroenterologists were approached and 165 (20%) responded. Sixty-one percent saw one to four patients annually with bowel symptoms after radiotherapy. Eighteen percent rate the current treatments as effective "often" or "most of the time". Forty-seven percent of gastroenterologists consider themselves "confident with basic cases", with 11% "confident in all cases". Fifty-nine percent thinks a gastroenterologist with a specialist interest should manage these patients. Although only 29% thinks a specific service is required for these patients, 34% rates the current service as inadequate. The ideal service was considered to be gastroenterology-led, multidisciplinary and regional. Low referral rates, poor evidence-base and poor funding are cited as reasons for the current patchy services.

Conclusions The low response rate contrasts with that from a parallel survey of clinical oncologists. This may reflect the opinion that radiation-induced bowel toxicity is not a significant issue, which may be because only a small proportion of patients are referred to gastroenterologists. The development of new, evidence-based gastroenterologyled services is considered the optimal way to meet the needs of these patients.

 $\label{eq:continuous} \textbf{Keywords} \ \ \, \textbf{Late effects} \cdot \textbf{Pelvic radiotherapy} \cdot \\ \textbf{Management} \cdot \textbf{Bowel} \cdot \textbf{Symptoms} \cdot \textbf{Gastrointestinal} \cdot \textbf{Pelvic radiation disease} \cdot \textbf{Enteropathy} \cdot \textbf{Proctopathy} \cdot \textbf{Proctitis} \cdot \\ \textbf{Enteritis} \cdot \textbf{Radiation} \cdot \textbf{Gastroenterologist} \\$ 

## Introduction

Seventeen thousand patients per year are treated with radical pelvic radiotherapy in the UK [1]. Survival is improving [2–4]. In parallel to improved survival and cure,



there has been an increase in chronic side effects of treatment, including gastrointestinal damage [5, 6]. The chronic side effects of radiotherapy also include bladder, bone and sexual dysfunction, but bowel symptoms have the greatest impact on quality of life [7].

The published incidence varies from 2% to 30% for rectal toxicity [8] and 5% to 15% for chronic radiation damage to the GI tract outside the rectum [9, 10], although recent published data suggest that radiation injury is rarely focal and often involves much more extensive changes than are frequently described [11]. The true extent of chronic gastrointestinal toxicity is underestimated [12]. Up to 90% of patients develop a permanent change in bowel habit after pelvic radiotherapy and in 50% of patients this adversely affects quality of life [13].

Bowel symptoms after pelvic radiotherapy do not necessarily equate to late radiation toxicity, with one third of patients having a diagnosis unrelated to the previous radiotherapy [14]. Twelve percent have either a recurrent malignancy or a new secondary tumour [14]. More than half of patients have two or more separate diagnoses causing their symptoms [14]. The underlying diagnoses are often easily treatable, e.g. lactose intolerance, bile acid malabsorption, small bowel bacterial overgrowth, druginduced diarrhoea or thyroid dysfunction [13]. In fact, gastroenterological assessment of these patients alters diagnosis in 64%, with curative therapy available for 27% of patients [15].

The UK Cancer Plan (2000) raised the standards of cancer treatment on a national level and improved outcomes for patients diagnosed with cancer through a multidisciplinary structured approach. Unfortunately, this has not been extended to patients with chronic, often complex, complications of their cancer treatment. The National Cancer Survivorship Initiative (2008) and the Survivorship Vision (2010), part of the Cancer Reform Strategy (2007), has identified access to specialist care for complications of cancer treatment as one of the four key needs of cancer survivors. However, these patients continue to receive suboptimal care due to a combination of poor patient reporting [16], poor clinician recognition [17], lack of GI specialists or expertise [11] and therapeutic nihilism [18].

We aimed to determine the current practice and opinion of British gastroenterologists with respect to the management of and services available to patients who develop chronic bowel symptoms, defined as symptoms which are present at least 6 months following pelvic radiotherapy. This group was chosen as gastroenterologists are not routinely involved in the management of acute gastrointestinal symptoms related to cancer treatments.



A questionnaire was developed with input from gastroenterologists and clinical oncologists with expertise in chronic side effects of radiotherapy. It comprised five sections including demographic data, referral patterns, management strategy, confidence in management and service provision. This was sent to all consultant gastroenterologists in the UK who are members of the British Society of Gastroenterology. Those who were exclusively academic or those with a purely hepatological practice were excluded.

Survey participants were divided into two groups: those with email addresses (701) and those without email addresses (165). Those with email addresses were sent the survey electronically using survey monkey by sending an email with the survey link. If the recipient did not respond, the email was sent again up to a maximum of three times. If there was still no response, the survey was posted out up to a maximum of two times. Those without an email address were sent a paper questionnaire with a stamped addressed envelope up to a maximum of two times. The time period between each time the survey was sent out was 15–20 days. The survey was conducted between December 2009 and April 2010.

### Statistical methods

Data was analysed using SPSS version 16. The majority of the results are expressed as simple frequencies, with percentages quoted as part of the whole group (n=165), or as part of a subgroup as stated. Qualitative data are reported by identifying key themes and reporting direct quotes.

As this was a survey of clinicians' views, there were no ethical implications, and as such, ethics committee approval was not sought.

## Results

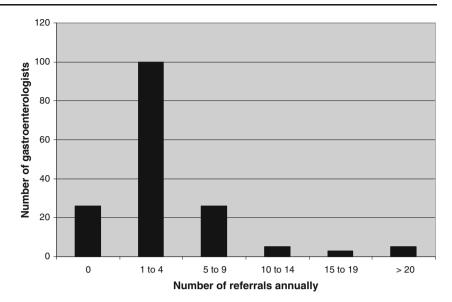
Eight hundred sixty-six gastroenterologists were identified in the UK. One hundred sixty-five responses (20%) were received.

## Background data

One hundred fifty-six respondents (96%) reported that they treat luminal gastrointestinal disease. Twenty-six (16%) do not see any patients with radiation-induced symptoms. The reported number of patients seen annually with GI symptoms following pelvic radiotherapy is shown in Fig. 1. Of note, only five (3%) gastroenterologists report being referred more than 20 such patients per year.



Fig. 1 The number of patients referred to individual consultants annually with chronic bowel symptoms following pelvic radiotherapy



## Referral patterns and management strategy

Gastroenterologists receive referrals from numerous sources. Seventy-one (43%) receive referrals from oncologists and 111 (67%) receive them directly from GPs. Referrals are also reported from colorectal surgeons by 71 (43%), urologists by 28 (17%) and gynaecologists by 53 (32%). The most frequent referral symptoms are stool frequency (116, 70%), rectal bleeding (115, 70%), urgency (108, 66%), loose stool (87, 53%) and faecal incontinence (74, 45%). The symptoms these patients have when referred is shown in Fig. 2.

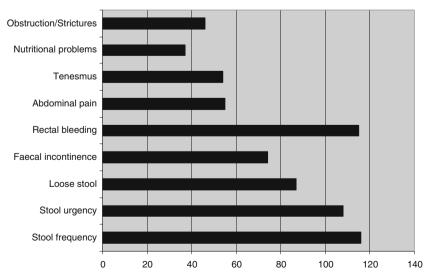
The investigations requested by gastroenterologists are shown in Fig. 3. A wide variety of treatments are prescribed by gastroenterologists to treat bowel symptoms in this patient population (Fig. 4). Only 22 (13%) rate currently available treatments as effective "often" and 8 (5%) "most

Fig. 2 Frequency of gastrointestinal symptoms in patients referred following pelvic radiotherapy

of the time". Ninety-six (58%) think the treatments are effective sometimes with 12 (7%) only considering them effective "rarely".

## Confidence in management

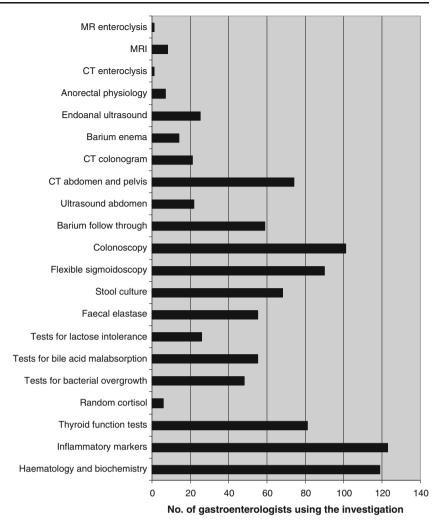
Gastroenterologists were asked to choose the statement that best described their confidence in managing patients with late-onset bowel symptoms after pelvic radiotherapy. Forty (24%) stated that they were "somewhat confident, but have minimal experience". Seventy-seven (47%) consider themselves "confident with basic cases, but would need sub-speciality advise with more complex cases", with 19 (11%) "confident in all cases" and considered themselves to have a specialist interest in this area. Five (3%) felt they were "not at all confident with no experience".



No. of gastroenterologists reporting referrals with the symptom



Fig. 3 The use of different investigations in patients with chronic bowel symptoms after pelvic radiotherapy

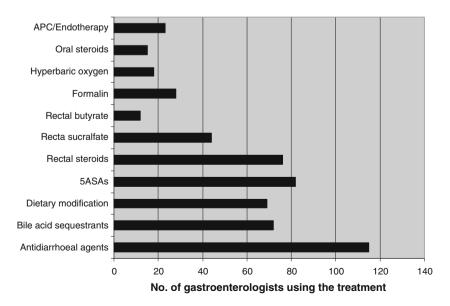


## Service provision

Ninety-seven (59%) respondents think that a gastroenterologist with a specialist interest should ideally manage these

Fig. 4 The use of different treatments in patients with chronic bowel symptoms after pelvic radiotherapy

patients. Thirty-one (19%) stated that they should be managed by a general gastroenterologist and 10 (6%) stated that they should be managed by a GI surgeon with a specialist interest. However, only 31 (19%) have a





gastroenterologist or GI surgeon with a specialist interest in their area.

Forty-eight (29%) think that a specific service is required for this patient group, with 65 (39%) stating that they do not know whether or not one is required. Seventy (42%) gastroenterologists rate the current service as "adequate", whereas 56 (34%) rate it as "poor" or "fails to meet the needs of patients". Only 12 (7%) think the service is "good".

The ideal components of a service

The key themes emerging from this open question regarding the ideal components of a service are listed in Table 1. Table 2 shows direct quotations.

Most of those surveyed felt there should be a multidisciplinary service led by a gastroenterologist with a specialist interest, with specialist nurse and dietician support and good links to clinical oncologists, colorectal surgeons and a nutrition team. Many felt that this should be a regional, tertiary service to enable rapid access to the whole range of diagnostic and therapeutic modalities required. It should disseminate information on management and be a hub of expertise, education and research. They also specifically mentioned the need for adequate resources to fund the service.

### Care and management of patients

The key themes emerging from this open question about the current care and management of this patient group are listed in Table 1. Table 2 shows direct quotations.

The current care and management is felt by many to be poor and inconsistent, with a lack of awareness of the importance and significance of this clinical scenario amongst gastroenterologists. Many state that, although there is a large cohort of patients affected, they think that chronic GI side effects of pelvic radiotherapy are not reported, recognised or referred. This may explain why some responding gastroenterologists report that they do not feel it is a significant issue. They also report that paucity of evidence and emphasis on the symptom of rectal bleeding

**Table 1** Comparison of the key themes emerging regarding current care and management and ideal components of a service

Reflections on current care and management	Ideal components of a service
Poor recognition of symptoms	Multidisciplinary team working
Low referral rates	Gastroenterologists with an interest
Inadequate patchy service	Links between relevant professionals
Inadequate patchy service	Regional tertiary service
Lack of funding to develop services	Access to all diagnostic and treatment modalities
	Well disseminated information on management strategies
	Expertise
	Education and research
	Resources

may be compromising the standard of management for this patient group. One respondent stated that they had tried to set up a specific service to improve the management of these patients, but no funding was provided.

#### Discussion

Although up to 50% of patients treated with pelvic radiotherapy develop significant chronic bowel symptoms, which equates to twice the number of patients diagnosed annually with Crohn's disease [11], this survey of British gastroenterologists had a low response rate. This is in contrast to a high response rate (61%) from a parallel survey of clinical oncologists [18] and may reflect the opinion amongst some gastroenterologists that this is not common or relevant clinical scenario.

Only a small proportion of affected patients are referred for gastroenterological evaluation and many gastroenterologists do not feel confident in managing them. This may reflect the lack of established routes of referral, lack of services and available expertise and poor communication. Treatments known to be ineffective are often prescribed, and investigations for common diagnoses following radiotherapy are not often used. This may reflect poor access to the necessary diagnostic tools and treatments in clinical practice, and may contribute to the opinion that treatments are ineffective. Low referral rates may also be compounding the perception that this is not a widespread or significant clinical problem.

The most common symptoms that gastroenterologists report as a reason for referral are frequency, urgency, loose stool and rectal bleeding. Tests for bile acid malabsorption, lactose intolerance and small bowel bacterial overgrowth are not commonly used despite the fact that these are common causes for these symptoms following pelvic radiotherapy [14, 18–23]. The most commonly used treatments are anti-diarrhoeal agents. Whilst this medication does have a role in symptomatic treatment, it should not replace systematic investigation to identify underlying GI diagnoses. Other



Table 2 Direct quotations on ideal components of a service and current care and management

Themes	Quotations
Ideal components of a servi	ice
Nature of service	"probably need regional service rather than local one"
	"Prompt, effective tertiary service"
	"Tertiary service for referral of complex cases would be of value"
	"Clear pathways and accessibility - needs also to be visible across health economy"
Multidisciplinary team	"Multidisciplinary support"
working	"Access to broad spectrum and experimental treatments"
	"MDT of interested physician, surgeon, radiologist specialist nurse"
	"Gastroenterology/dietetics input with interested surgeon"
	"A good gastroenterologist"
	"Multidisciplinary team who meet regularly"
Expertise	"Someone needs to take an interest, collect the cases and thus increase his/her expertise"
	"Good background knowledge of the condition"
	"Expertise and accessibility"
Resources/funding	"Experienced staff with adequate resources"
	"Availability of all therapeutic and diagnostic modalities"
	"Good endoscopy facilities, expert radiologists, excellent dieticians and even psychological services"
Education	"Well disseminated info on how to investigate and treat these patients"
Current care and management	ent
Reflections on the current	"It is mostly poor around the country"
service	"Generally poorly treated"
	"I feel there is a real paucity of service for these patients"
	"There is too much emphasis on therapy to reduce bleeding"
	"Lack of consistent approach, adequate literature and awareness among gastroenterologists re the different types of radiotherapeutic techniques and their influence on bowel dysfunction"
Recognition of GI symptoms	"Despite it being well recognised, oncologists and gynaecologists and GPs are very slow to recognise it and address the problem"
Referral rate	"There is a large group of patients out there who do not even get referred to the right people and their suffering goes unrecognised and their needs remain unmet"
	"We don't see much considering the large amount of radiotherapy given at Clatterbridge"
	"I get very few referrals. If there are lots like you say, they either put up with it, or don't get referred"
	"I guess most patients are never referred - otherwise we would see a lot more patients"
	"Amazing they do not get referred, when they are there. Why not?"
Demand for service	"Too few patients to develop business case for developing local service"
	"Not a major issue"
	"Don't see enough of it to feel it's a major issue in my practice"
	"My perception is that this isn't common, and that there isn't a need for a specific local service"
Funding	"I have tried to set up specialist clinics for late onset bowel dysfunction but no specific funding"
	"Evidence base lacking therefore services remain patchy"
Research	"Lack of evidence base"
Future services	"We are just looking into whether we need to set up a specific service in our area"

commonly used treatments are rectal steroids and 5ASAs, for which there is no good evidence for use in the management of radiation-related GI injury [24–26].

The management practice elicited from this survey raises the issue of training for both clinical oncologists and gastroenterologists. Education could raise the standards of management generally and greater emphasis on the consequences of cancer treatments during higher specialist training would comprehensively address this shortfall in knowledge in the future. This is particularly important given there are two million cancer survivors in the UK and this number is increasing at a rate of 3% per annum [27].

Many gastroenterologists consider that specialist gastroenterology-led multidisciplinary services are required



to meet the needs of this patient group and are dissatisfied with the quality of current services:

There is a large group of patients out there who do not even get referred to the right people and their suffering goes unrecognised and their needs remain unmet

This is in keeping with British clinical oncologists, as demonstrated in a parallel survey, which showed that 75% of oncologists think that a gastroenterologist with a specialist interest should manage these patients, 65% think a specific service is required and 52% rate the current service as inadequate [18].

In comparison to a survey of British gastroenterologists in 2003 [15] which had a 50% response rate, the findings concurred in many respects. Most gastroenterologists surveyed in 2003 saw a median of 3 patients per year and only 18% felt they could often help patients. Whilst this may initially seem disheartening, there is an increasing momentum at a national level with the National Cancer Survivorship Initiative (2008), increasing recognition amongst clinical oncologists and the development of local patient user groups.

This survey focuses specifically on the management of gastrointestinal symptoms following pelvic radiotherapy. There are very few services available currently in the UK for consequences of pelvic radiotherapy and several potential models could be implemented. It is likely that the model of care used would need to be tailored to regional need. One of the few designated services for pelvic radiation disease in the UK is based at the Royal Marsden Hospital, but it is unlikely that this model of care could be effectively exported to a more rural region of the UK. There is also a paucity of services for other consequences of pelvic radiotherapy including bladder dysfunction. Patients with urological malignancies often have follow-up with urological surgeons, but otherwise there are few models of care on which to base a new gastroenterology service.

Whilst this survey begins to highlight some of the issues regarding the current management of patients who develop chronic gastrointestinal symptoms following pelvic radiotherapy, several questions remain. The current literature clearly demonstrates that the quality of life and social functioning of patients is adversely affected by GI symptoms following pelvic radiotherapy [13, 28, 29]. It has also been demonstrated that patients do not always volunteer information about symptoms, often considering them inevitable consequences of treatment or age and that there is nothing that can be done [16, 30]. However, the effect of improved gastroenterological services to manage these symptoms on patients' quality of life and patient satisfaction has not yet been adequately addressed. Also, we do not currently have clear criteria to identify which patients require gastroenterology assessment. Whilst it is likely that all patients with GI

symptoms would benefit from specialist evaluation, this may not be realistic in the current economic climate. Further work is needed to identify which patients should be referred and methods of risk stratification. Other models of providing services for this patient group are currently being investigated, including the possibility of care being provided by specialist nurses alongside physicians [31].

### Limitations

There was a low response rate to this survey, despite sending it up to five times in both paper and electronic form. This raises the potential for systematic bias, particularly non-respondent bias, i.e. those who responded are likely to be those most interested in this subject and may not accurately reflect the opinions of all British gastroenterologists. However, the opinions expressed in the survey were not uniform and included a minority of people who do not feel that chronic bowel symptoms after pelvic radiotherapy are a significant or relevant problem. Another issue may have been the initial questions on the survey regarding personal details of the respondents. Although this was optional, it may have raised concerns in some potential respondents regarding anonymity.

The questionnaire was developed with input from clinical oncologists and gastroenterologists with expertise in the side effects of radiotherapy. It is, however, not a validated tool and was developed specifically to gauge current practice and opinion. Given that this is not a prospective study reporting actual practice, it is a survey establishing reported practice, it is possible that some of the results may reflect what gastroenterologists think is happening, as opposed to what is actually happening.

## **Conclusions**

Gastroenterological assessment is necessary to effectively manage patients who develop gastrointestinal symptoms after pelvic radiotherapy [11]; however, currently services and specialist expertise are sparse. Better communication between clinical oncologists and gastroenterologists will enable appropriate services to be developed which satisfy the needs of both clinicians and this often overlooked patient group.

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Conflict of interest None declared.



## Appendix 1: Gastroenterologists' survey

Backg	round Data	
1.	Name & e-mail address (optional):	
2.	Who is your current employer?	
3.	What is your area of interest?	
	Please tick more than one option if applicable.	
	□ General gastroenterology/hepatology □ Luminal gastroenterology □ Nutrition □ Endoscopy □ Hepatobiliary □ Hepatology □ Transplant hepatology □ Academic gastroenterology □ Academic hepatology □ Other, please specify	
4.	Do you treat people with luminal gastroenterological diseases?	
	□ Yes □ No	
5.	How many patients, on average, do you treat with late onset bowel dysfunction post pelvic radiotherapy per year?	
	<ul> <li>□ 0</li> <li>□ 1 - 4</li> <li>□ 5 - 9</li> <li>□ 10 - 14</li> <li>□ 15 - 19</li> <li>□ &gt; 20</li> </ul>	
Referr	al Patterns	
1.	Which specialists refer you patients with late onset bowel dysfunction post-pelvic radiotherapy?  Please tick more than one option if applicable.	
	□ GP □ Oncologist □ Colorectal Surgeon □ Urologist □ Gynaecologist □ Other, please specify	
2.	What symptoms do patients with late onset bowel dysfunction post-pelvic radiotherapy get referred with?  Please tick more than one option if applicable.	



Stool frequency Stool urgency Loose stool

Faecal incontinence

	□ Rectal bleeding
	□ Abdominal pain
	□ Tenesmus
	□ Nutritional problems
	□ Obstruction/strictures
	□ Other, please specify
3.7	4.64
Manag	gement Strategy
1.	Which investigations would you consider performing on patients referred with late onset bowel dysfunction post-pelvic radiotherapy?
	Please tick more than one option if applicable.
	Routine biochemistry/haematology
	☐ Inflammatory markers ☐ Thursid function tests
	<ul><li>☐ Thyroid function tests</li><li>☐ Random cortisol</li></ul>
	<ul> <li>□ Breath testing/duodenal aspirate for bacterial overgrowth</li> <li>□ Tests for bile salt malabsorption, e.g. empirical bile acid binder/SehCAT</li> </ul>
	scan/breath test
	☐ Breath testing/dietary exclusion trial for lactose intolerance
	□ Faecal elastase
	□ Stool culture
	□ Flexible sugmoidoscopy
	□ Colonoscopy
	□ Barium follow through
	□ US abdomen
	□ CT abdomen/pelvis
	□ CT virtual colonography
	□ Barium enema
	□ Endoanal US
	□ Other, <i>please specify</i>
2.	Which of the following treatments have you used in the treatment of late onset bowel
	dysfunction post-pelvic radiotherapy?
	Please tick more than one option if applicable.
	□ Antidiarrhoeals
	□ Bile acid sequentrants
	□ Dietary modification
	□ 5ASA, e.g. mesalazine
	□ Rectal steroids
	□ Oral steroids
	□ Rectal sucralfate
	□ Oral antibiotics, <i>please specify the type</i>
	□ Rectal butyrate
	□ Endotherapy, <i>please specify</i>
	□ Formalin
	☐ Hyperbaric oxygen
	□ Other, please specify
Confid	ence in Management
1.	How confident do you feel in managing patients with late onset bowel dysfunction post-pelvic radiotherapy?
	<ul> <li>□ Not at all confident, no experience</li> <li>□ Somewhat confident, but minimal experience</li> </ul>
	•



	complex cases  Confident in all cases, I consider myself to have a specialist interest in this area
2.	Do you feel that the currently available treatments for late onset bowel dysfunction post-pelvic radiotherapy are effective in improving symptoms in your patients?
	<ul><li>□ Rarely</li><li>□ Sometimes</li><li>□ Often</li><li>□ Most of the time</li></ul>
Servic	e Provision
1.	Who do you think should ideally manage these patients?
	<ul> <li>Oncologist</li> <li>General gastroenterologist</li> <li>Gastroenterologist with a specialist interest</li> <li>General GI surgeon</li> <li>GI surgeon with a specialist interest</li> <li>GP</li> <li>Other, please specify</li> </ul>
2.	Is there a gastroenterologist or GI surgeon in your area who you has a specific interest in late-onset bowel dysfunction post-pelvic radiotherapy?
	□ Yes □ No
	If you wish, please provide their name
3.	Do you think a service is required specifically for patients with late-onset bowel dysfunction post-pelvic radiotherapy?
	<ul><li>Yes</li><li>No</li><li>Don't know</li></ul>
4.	How would you describe the current service provided for patients with late-onset bowel dysfunction post-pelvic radiotherapy in your area?
	<ul> <li>□ Good</li> <li>□ Adequate: in most cases patients needs are met</li> <li>□ Poor: some services available but needs of the patients not consistently met</li> <li>□ Fails to meet the needs of patients at all</li> </ul>
5.	What are the ideal components of a local service?
6.	Do you have any other comments about the care and management of patients with late-onset bowel dysfunction post-pelvic radiotherapy?

Confident with basic cases, but would need sub-speciality advise with more

Thank you very much for taking the time to complete this questionnaire.



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