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# Colorectal patient information guidance

June 2015

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## Introduction

Patient information is an integral part of each patient's journey and central to providing a high quality patient experience. The guidance set out below forms part of the LCA Colorectal Cancer Clinical Guidelines and intends to:

- improve consistency of written information given across the LCA
- tailor information so that it can best meet patients' needs
- support healthcare professionals in accessing, prescribing and dispensing information in a timely and accessible manner.

## When to offer patient information?

Written information should be offered to colorectal cancer patients on a continuing basis, with particular importance given to each of the following points along the pathway:

- pre-diagnosis
- diagnosis
- at the start of a treatment episode
- at the end of treatment episode
- other transition points, e.g. entry into cancer survivorship, transfer to palliative care.

## Why offer written information?

In line with the NHS Constitution, the aim is to:

*“offer easily accessible, reliable and relevant information to enable individuals diagnosed with colorectal cancer to fully participate in their own healthcare decisions, and to support them in making choices.”*

## What information should be offered?

There is a comprehensive range of nationally produced booklets and factsheets developed by reputable cancer charities, the NHS and commercial companies that cover all aspects of the colorectal cancer pathway. In addition many Trusts have developed their own written patient information.

Whilst healthcare professionals should always aim to provide an individualised information prescription for their patients according to their needs, the LCA Colorectal Pathway Group recommends that all patients are offered at least one written information resource on each of the following aspects of their care:

- *On first contact with the clinical nurse specialist*, the key worker leaflet should be offered and should include the following:
  - who the service is for
  - the name of the colorectal cancer nurse(s) involved in their care
  - how the clinical nurse specialists can be contacted
  - what the clinical nurse specialists can offer

- a section on Holistic Needs Assessment.

An example of a key worker leaflet with appropriate wording is shown in [Appendix 1](#).

- Information explaining any *investigations*
- Information explaining the *diagnosis*
- Information explaining *treatment*. At least one information resource should be offered to explain any treatment proposed whether surgery/chemotherapy/radiotherapy or other. This applies to both primary and secondary treatments.
- Specific information after treatment to support *recovery* and address any consequences of that treatment.
- Specific information about after-care/follow-up to support cancer *survivorship* (i.e. individuals living with and beyond cancer).

A list of nationally-available information resources is shown in [Appendix 2](#), which offers information for each of these six points in the patient's pathway. This list should be used to check what information exists at each time point but also it could constitute the patient's information prescription and be given to the patient. The information in [Appendix 2](#) should then form part of the patient record and be filed in their notes (electronic or hand held).

Locally-developed information may be used if the information is unavailable from national information sources or the information required needs to be tailored to that patient. Any locally produced information must follow the Trust's patient information development process. This usually involves working through a checklist which stipulates patient involvement and the quality information standards that must be adhered to, followed by the sign off process by the Trust's patient information committee or equivalent. An example checklist can be found in [Appendix 3](#).

## How should information be offered?

Information prescriptions are advocated in order to assess need, review information choices and to jointly decide with each individual what information they would like at that time. At each of the defined points on the pathway, healthcare professionals should:

- conduct an assessment of the patient's information need
- discuss the range of information resources available
- select the resources which will best meet their information need
- review if their information needs have been met.

Information prescriptions can be created using the NHS Choices website:

<http://www.nhs.uk/ipg/Pages/IPStart.aspx>

Assessment of information needs should be incorporated into any clinical contact but may become a more formal assessment using the above steps during a face-to-face consultation, for example when a patient is seen in clinic or during a discussion over the telephone. The patient's information needs may be elicited during a Holistic Needs Assessment. For an example of how this might work in practice, see [Appendix 4](#).

## Who should provide patient information?

It is the responsibility of the whole multidisciplinary team to offer patients appropriate information at each stage of their pathway, as patients rely upon the services of many different departments during their cancer diagnosis and treatment.

The colorectal clinical nurse specialist supports patients along their pathway and therefore plays a pivotal role both in the provision of information and in monitoring the relevance and effectiveness of information given throughout the patient pathway.

## Appendix 1: Example key worker leaflet

Below is an example of a key worker leaflet. This leaflet should be offered at first contact with the CNS and include the following:

- who the service is for
- the name of the colorectal cancer nurse(s) involved in their care
- how the clinical nurse specialists can be contacted
- what the clinical nurse specialists can offer
- where the patient can get further information
- a section on Holistic Needs Assessment.

Trusts should ensure any locally developed key worker leaflet incorporates the above best practice information.

## Useful Contacts

### Macmillan Cancer Information Service at xxxxxx

Tel: xxxxxx

Email: xxxxxx

### The South East Cancer Help Centre

Tel: 020 8668 0974

Email: [info@sechc.org.uk](mailto:info@sechc.org.uk)

Web: [www.sechc.or.uk](http://www.sechc.or.uk)

### Macmillan Cancer Support

0808 808 00 00

### Beating Bowel Cancer

T: 020 8892 5256

Web: [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)

National charity working to raise awareness of symptoms, promote early diagnosis and encourage open access to treatment choices for those affected by bowel cancer.

### Out of hours advice

After hours and at the weekend you can call the hospital switchboard on xxxxxxxxxx and ask them to bleep the on call surgical registrar.

## The Team

The colorectal team consists of xxxxxx

Surgeons:

xxxxxxx

Oncologists:

xxxxxxxxx

Colorectal Advanced Nurse Practitioner:

xxxxxxxxxxx

### Colorectal Advanced Nurse Practitioner contact details

Tel: xxxxxxxx Ext: xxxxx Pager: xxxxx

Email:

xxxxxxxxxxx

### Support groups

#### Cancer Counsellors

xxxxxxxxxxx

#### Macmillan/CAB Advice Service

01689 808135/Fax 01689 845105

**If you need advice, support or information, we are here to help.**

## Your CNS (Clinical Nurse Specialist)/Colorectal Advanced Nurse Practitioner

A guide for patients and carers

### Your key worker is



### Your key worker

Your key worker is xxxxxxxx who is a colorectal advanced nurse practitioner. xxxxx is a registered nurse with specialist training and experience in nursing people with and colorectal problems.

S/he is based at xxxxxxxx hospital and works closely with other nurses, doctors and healthcare professionals. Please feel free to contact xxxxx at any stage in your treatment, especially if you have concerns or questions that need answering

### About the key worker role

xxxxx is available from the difficult time of diagnosis to offer you and your family support and advice.

S/he will be with you through all of your investigations and treatments and will be your main point of contact at every stage of your illness.

While at home, you or your family may think of questions about your diagnosis, treatment, diet or lifestyle. Please ask xxxxx who will try and answer them.

xxxxx can also help you if you need to contact any of your doctors and specialists for further information or advice.

### Questions and Comments?

If you have a problem when in hospital that the nurses and doctors are unable to resolve, you can contact the **Patient Advice and Liaison Service (PALS)** who will be happy to help you.

You can find PALS in xxxxxxxxxxxxxxxx. The PALS office is open to callers from xam to xpm, Monday to Friday, telephone number: xxxxxxxx

### Smoking

If you would like help to stop smoking before you come into the hospital, there is a smoking cessation helpline that you can call on xxxxxxxx. We can also offer nicotine replacement therapy (patches) to patients who want it.

### Data protection

During your visit you will be asked for some personal details. This is kept confidential and used to plan your care.

**We will give you all the information you need to help you to make informed decisions.**

Information about you may be used for audit purposes and shared within the NHS. Your consent is required for this which you have a legal right to refuse. If you wish to exercise your legal right to have access to all information held about you by the Trust or you would like to talk to someone about data protection, please contact the Data Protection Officer on xxxxxxxx.

### Holistic Needs Assessment (HNA)

People who have had a cancer diagnosis can be affected in a variety of ways. 'Holistic' means whole, which includes your physical, emotional, social and financial well-being. Often patients do not raise issues important to them with their doctors and nurses.

A Holistic Needs Assessment is a process designed to enable you to share information with your doctors and nurses which is important for the treatment and care you receive. It can help identify any concerns that you wish to discuss with them. The process can help your multidisciplinary team target support and care for you. You do not have to have a Holistic Needs Assessment but many people find it opens up discussions with their doctors and nurses about their concerns which may not otherwise be raised.

If you feel that an HNA would be helpful, please talk to a member of your treating team or contact xxxx whose details are listed on this leaflet.

## Appendix 2: LCA core content for written patient information

This information is to be used as part of the patient record and should be filed in their notes (electronic or hand held).

Information content	Colon, rectal and anal cancer information	Date given	By who and sign
<b>INITIAL CONTACT</b>			
Key worker details	Local information leaflet (meeting LCA minimum standard)		
<b>INVESTIGATIONS</b>	Patient should be offered written information for any investigation proposed	<b>Date given</b>	<b>By who and sign</b>
Colonoscopy/flexible sigmoidoscopy	Local information		
CT scan	Local information		
MRI scan	Local information		
PET scan	Local information		
Understanding Bowel Cancer: Detect and Diagnose	Beating Bowel Cancer		
Diagnosing bowel cancer	Bowel Cancer UK		
Are you worried about bowel cancer?	Macmillan Cancer Support		
Understanding bowel cancer screening	Local/Macmillan Cancer Support		
<b>AT DIAGNOSIS</b>	One relevant booklet explaining the cancer diagnosis should be offered	<b>Date given</b>	<b>By who and sign</b>
Understanding Colon Cancer	Macmillan Cancer Support		
Understanding Rectal Cancer	Macmillan Cancer Support		
Understanding Bowel Cancer	Bowel Cancer UK		
Bowel Cancer – your treatment your pathway	Beating Bowel Cancer		
Understanding Anal Cancer	Macmillan Cancer Support		
Understanding Secondary Liver Cancer	Macmillan Cancer Support		
Specific information on type of cancer	Local/charity Information		

<b>TREATMENT: SURGERY</b>	At least one relevant resource explaining the proposed surgery should be offered	<b>Date given</b>	<b>By who and sign</b>
Bowel Cancer – Your surgery your operation	Beating Bowel Cancer		
Enhanced recovery after surgery	Local Information		
Specific information on type of surgery	Local/charity information		
Colonic stents	Beating Bowel cancer		
Surgery for advanced colon/rectal cancer	Cancer Research UK		
Stoma booklet – as needed	Various companies		
Your pathway	Beating Bowel Cancer		
<b>TREATMENT: CHEMOTHERAPY/RADIO THERAPY</b>	At least one relevant resource explaining the proposed cancer treatment should be offered	<b>Date given</b>	<b>By who and sign</b>
Understanding radiotherapy	Macmillan Cancer Support/local information		
Understanding chemotherapy	Macmillan Cancer Support/local information		
PICC/Hickman line	Local information		
Specific chemotherapy regimes	Factsheets on NHS Choices		
Targeted therapies and biomarkers	Beating Bowel Cancer		
Clinical trials	Beating Bowel Cancer		
K-RAS	Beating Bowel Cancer		
Monoclonal antibodies – Avastin	Factsheets on NHS Choices		
Monoclonal antibodies – Erbitux	Factsheets on NHS Choices		
Chemotherapy for advanced colon/rectal cancer	Factsheets on NHS Choices		
Advanced bowel cancer: Treating metastases	Beating Bowel Cancer		
Radiofrequency ablation	Macmillan Cancer Support website		
Palliative care	Macmillan Cancer Support		
<b>RECOVERY AND TREATMENT CONSEQUENCES</b>	As needed	<b>Date given</b>	<b>By who and Sign</b>
Returning Home	Beating Bowel Cancer		
Side-effects of bowel cancer chemotherapy	Macmillan Cancer Support		
Stoma reversal	Local/Beating Bowel Cancer		
Regaining bowel control	Beating Bowel Cancer		
Managing peripheral neuropathy	Beating Bowel Cancer		
Coping with fatigue	Macmillan Cancer Support		
Side effects of cancer treatment	Macmillan Cancer Support		

Worrying about cancer coming back	Macmillan Cancer Support		
Body image and cancer	Macmillan Cancer Support		
Cancer, you and your partner	Macmillan Cancer Support		
How are you feeling? The emotional effects of cancer	Macmillan Cancer Support		
Managing the late effects of bowel cancer treatment	Macmillan Cancer Support		
Managing the late effects of pelvic radiotherapy in men/women	Macmillan Cancer Support		
<b>SURVIVORSHIP</b>	At least one resource explaining any proposed cancer treatment should be offered	<b>Date given</b>	<b>By who and sign</b>
Ten Top Tips: what to do when treatment ends	Macmillan Cancer Support		
Life after cancer treatment	Macmillan Cancer Support		
Living with Bowel Cancer – Eating Well	Beating Bowel Cancer		
Beyond Bowel Cancer – Living Well	Beating Bowel Cancer		
Support for you	Beating Bowel Cancer		
Maintaining a healthy lifestyle	Macmillan Cancer Support		
Your diet: living with and beyond bowel cancer	Bowel Cancer UK		
Managing your follow-up	Beating Bowel Cancer		
Supported self-management	LCA/local information		
<b>OTHER</b>	As needed	<b>Date given</b>	<b>By who and sign</b>
Help with the cost of living with cancer	Macmillan Cancer Support		
Free prescriptions	Macmillan Cancer Support		
Getting travel insurance	Macmillan Cancer Support website		
Cancer Drugs Fund	Beating Bowel Cancer		
Holistic Needs Assessment	LCA		
Guide to benefits and financial help	Macmillan Cancer Support		
What to do if treatment isn't available	Beating Bowel Cancer		
Information on stomas	Stoma companies/Bowel Cancer UK		

## Specialist Information Resource

<b>DIETETIC INFORMATION CONTENT</b>	Colon, rectal and anal cancer information	<b>Date given</b>	<b>By who and sign</b>
Managing treatment symptoms and side effects	As needed		
Eating problems and cancer	Macmillan Cancer Support		
Eating with a low appetite	Bowel Cancer UK		
<b>STOMAS</b>	As needed	<b>Date given</b>	<b>By who and sign</b>
Nutritional guidelines for people who have a colostomy	Colostomy Association		
Dietary strategies for people who have an ileostomy	Local information		
<b>SURVIVORSHIP</b>	As needed	<b>Date given</b>	<b>By who and sign</b>
Eat well for life	World Cancer Research Fund		
A closer look at alcohol	World Cancer Research Fund		
Red and processed meat: finding the balance for cancer prevention	World Cancer Research Fund		
10 top tips for a healthy weight	Cancer Research UK		
Fibre after bowel cancer	Bowel Cancer UK		
Fruit and vegetables – how to get five-a-day	British Dietetic Association		
<b>SURVIVORSHIP: COOKBOOKS</b>		<b>Date given</b>	<b>By who and sign</b>
Everyday eating	World Cancer Research Fund		
Meals for one	World Cancer Research Fund		
One pot wonders	World Cancer Research Fund		
Healthier home baking	World Cancer Research Fund		
Country stews and casseroles	World Cancer Research Fund		
Comforting cuisine	World Cancer Research Fund		
<b>SURVIVORSHIP: HEALTH TOOLS</b>		<b>Date given</b>	<b>By who and sign</b>
5 a day diary	World Cancer Research Fund		
Alcohol diary	World Cancer Research Fund		
At a glance: making sense of food and drink labelling	World Cancer Research Fund		

OTHER	As needed	Date given	By who and sign
When to seek professional advice	Bowel Cancer UK		
Eat well, spend less	British Dietetic Association		

**Supporting dietetic guidance**

We recommend that you seek dietary advice given by a registered dietitian. However, for initial dietary advice you can choose a suitable factsheet or booklet for the stage of cancer treatment from the list above. Care should be taken to choose written information which meets the individual need of your patient, as not all resources will necessarily be suitable for each patient.

The booklets and factsheets listed here are not a substitute for dietary advice given by a registered dietitian or a formal medical diagnosis and patients should be referred to a dietitian by healthcare professionals in hospital, via their GP and in some cases a self-referral can be made. Generalised dietary advice during surgery and chemotherapy or radiotherapy is often not appropriate or safe and has therefore not been included in the list above. Once recovered from treatment patients may be given more generalised healthy eating advice. If you are unsure, always speak to a dietitian for tailored dietary advice.

The content of the list will be reviewed annually by the LCA Colorectal Pathway Group

## Appendix 3: Checklist for writing patient information

This checklist must be completed before your leaflet is submitted to the Patient Information Group.

Title of document:

Author's name:

Ref:

		Yes/No	Comments
<b>1.</b>	<b>Before you start</b>		
	Have you investigated other options including the EIDO database and national materials?		
	Have you consulted with colleagues, patients and clinical experts?		
	In what format will the information be produced and how will it be distributed?		
<b>2.</b>	<b>Funding</b>		
	Do you have a budget for designing and printing your leaflet?		
	If so, has it been approved by your manager?		
<b>3.</b>	<b>Writing your text. Have you included the following?</b>		
	Introduction – explaining what the leaflet is for		
	Simple description of condition and/or treatment		
	Brief description of treatment options		
	Benefits of treatment		
	Risks and side effects		
	Any alternatives (please state if none)		
	Preparation instructions for specific procedures e.g. medication, fasting		
	Clear explanation of treatment process e.g. pre-op assessment, day of admission		
	Do's and don'ts on going home What to expect from the recovery stage		
	Follow-up arrangements and department/staff contact details		
	Contact addresses for well-regarded external sources of support		
	Contact address and phone numbers for your department or the Trust		
	Have you consulted the NHS patient information guidelines?		

	Is your document written in plain English with no abbreviations or jargon?		
	Have you included the Trust address, relevant contact details, PALS information as well as information on visiting times and infection control?		
<b>4.</b>	<b>Evaluation</b>		
	Have two key clinical members/consultants signed off the text for accuracy of medical content?	Sig 1: Print Sig 2: Print	
	If the leaflet discusses the use of medication has it been approved by pharmacy? If no, consult with your local medicine management/pharmacy advice committee.		
	Have you sent your text to the communications department for proofreading?		
	Have you made corrections/clarifications as requested?		
	Have you inserted the standard text which informs patients of how they can get access to an interpreter or the leaflet in other formats (Braille, audio)? This is available from the communications department.		
<b>5.</b>	<b>Production/Presentation</b>		
	If professionally designing and printing, have you approved the quote? How many copies do you need?		
	If using internal template, have you used Arial font 12 point (or your Trust approved standard), avoided CAPITALS, underlining, refrained from using clip-art. Have you investigated internal printing options?		
<b>6.</b>	<b>Review/Archive</b>		
	Have you included a date of publication and a review date? Review every two years.		
	Have you included the reference number given to you by communications department?		

<b>Author approval</b>	
Name	Date
Signature	

<b>Communications approval</b>	
Name	Date
Signature	

<b>Patient information group approval/comments</b>	
Name	Date
Signature	

## Appendix 4: Checklist for post-treatment outpatient appointment

Addressing a patient's information needs will be integral to any consultation. During their post-treatment review, the information prescription should include the following:

- Assess patient's understanding of treatment received.
- Check their understanding of histology, discuss what it means in terms of risk of recurrence and offer written information.
- Conduct assessment of information need as part of broader assessment of care needs and concerns.
- Discuss expected recovery in the short, medium and the longer term.
- Discuss surveillance schedule, with rationale and what to expect over 5 years.
- Advise of any late effects of treatment.
- Discuss alert systems and how to re-enter services.
- Discuss the value in healthy lifestyle and benefits of exercising, eating healthily, not smoking and moderating alcohol.
- Offer the range of available written resources available including:
  - living well/life after cancer
  - eating well
  - moving more
  - looking after self, after cancer/10 top tips
  - managing your follow-up/supported self-management.
- Discuss services and resources that will remain available to them including benefits adviser, psychological support, social services etc.
- Ensure written information given about local and national support groups.
- Explain about entitlement to cancer care review.
- Ask if all information needs have been covered and reiterate that if they have further information need to know now, opportunity via telephone helpline.
- Ensure patient has key worker contact information card and knows who to call for further advice.