

Embracing the information revolution from 'across the pond'

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SLA President 2014

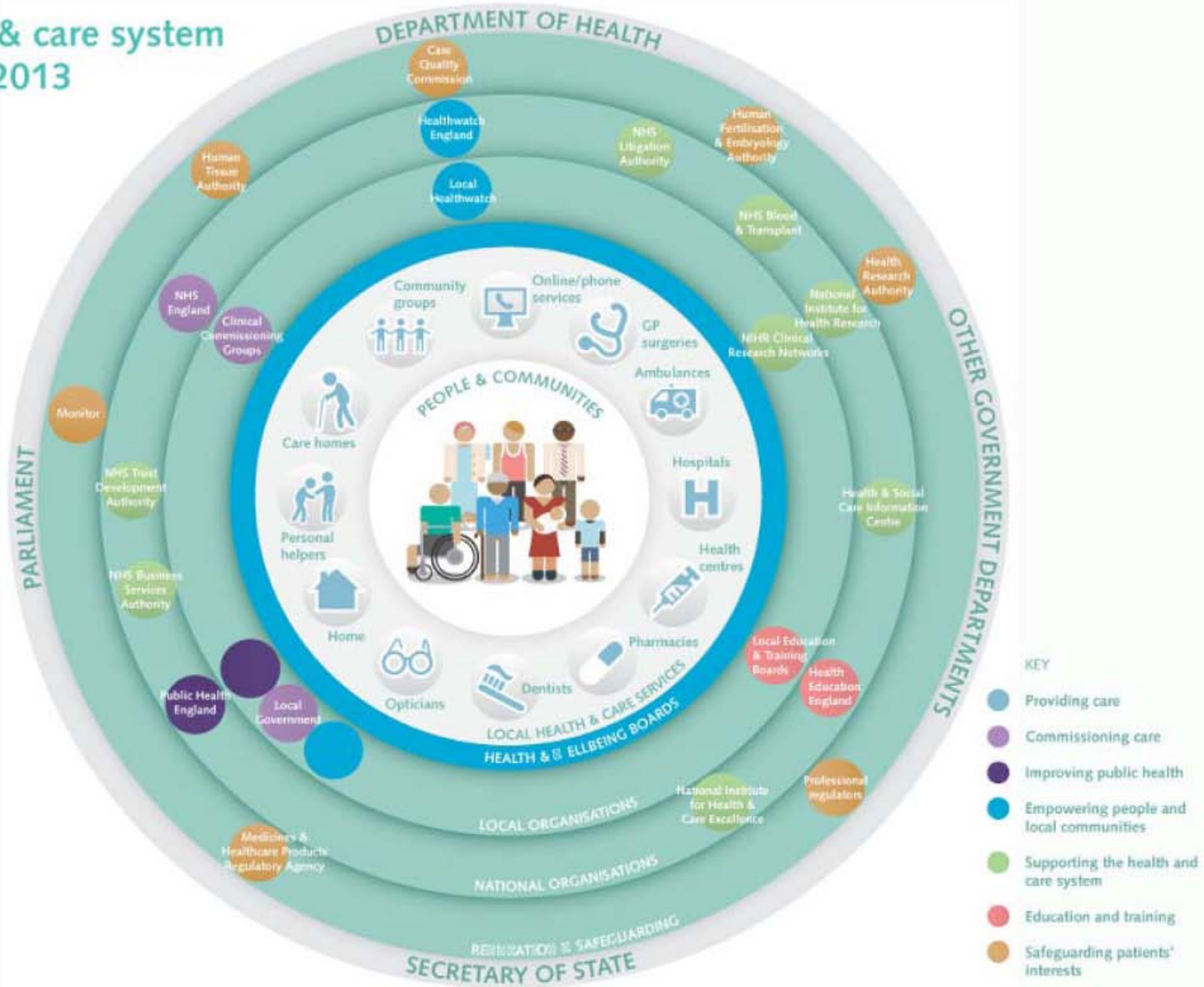
PHTD spring meeting Baltimore 1 April 2014



[Jenica Rogers @jenica26 Mar 17](#)

Ever wonder what a month of American medical bills looks like, when, in that month, you had a baby? Now you know

The health & care system from April 2013





The National Health Service (NHS)



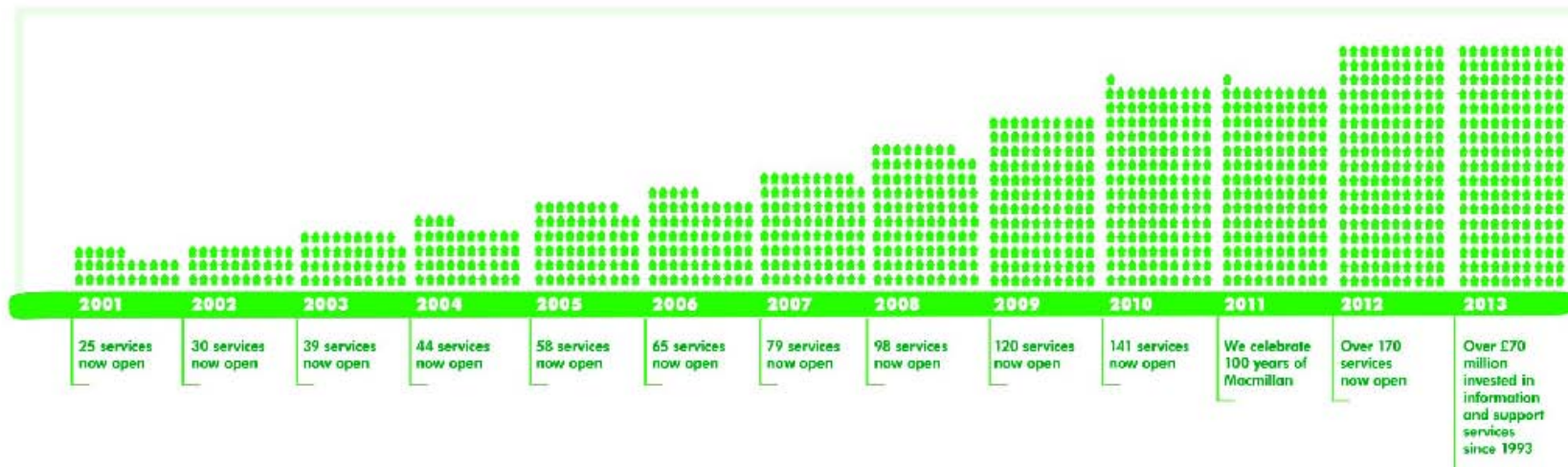
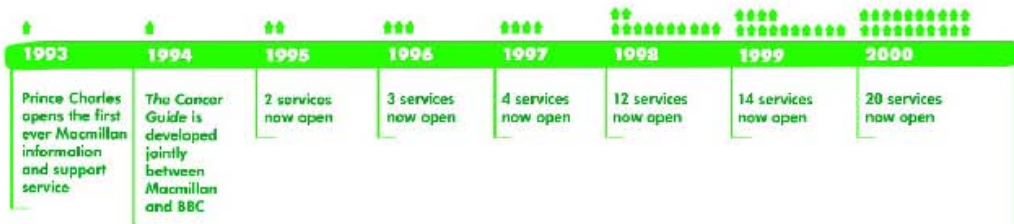
- 1.7 million staff
- Over 63.2 million patients
- £108.9 billion budget 2012/13
- Deals with 1 million patients every 36 hours

Source: www.nhs.uk

CELEBRATING 20 YEARS OF OUR INFORMATION AND SUPPORT SERVICES

1993-2013

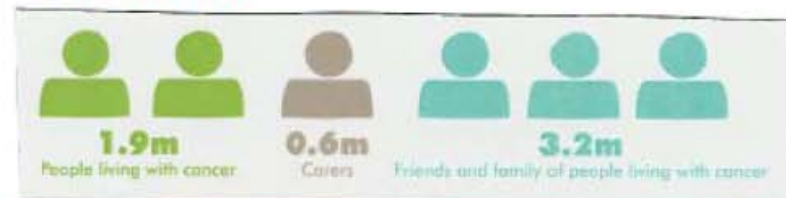
we can make sure no one faces cancer alone.



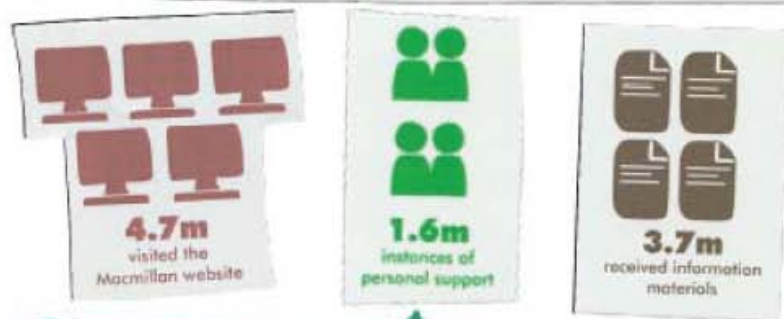


REACHING

In 2012 our services reached more people than ever before – 5.7 million in total.



These 5.7 million people used our services 9.9 million times.



We divide our personal support into four different services:



DEEPER, MORE PERSONAL SUPPORT IS CRUCIAL TO US
ACHIEVING OUR 9 OUTCOMES. WHAT WE NEED TO DO:
INSPIRE MORE PEOPLE TO JOIN THE MACMILLAN TEAM

Note: The totals in the centre section add up to more than 9.9 million due to rounding. The 1.6m instances of personal support and the totals shown in the lower section of this page do not necessarily represent unique people we helped, as some received support through more than one Macmillan service.

AND IMPROVING

These services improved the lives of people affected by cancer in many different ways:

Healthcare 735,570 people

Our healthcare professionals are valued for improving the quality of care and experience of people living with and beyond cancer – people just like Paul.

People like Colwyn, my Macmillan debriefers are so important. They help you get on with your life.
Paul

Information 585,362 people

Having access to the right information enables people affected by cancer to feel more in control and less stressed.

91% of callers to our Support Line said we listened to them and understood their needs.

Financial 180,780 people

Our expert financial support and guidance service makes sure people affected by cancer don't face money worries alone.

In 2012 we helped people affected by cancer access £245.6 million in benefits, grants and other financial support.

Practical and emotional 59,133 people

We help people cope with the emotional effects of cancer and also provide practical support to do everyday things like shopping and gardening.

We helped Beverly set up the Support group 'Keeping Abreast' for women diagnosed with breast cancer facing reconstructive surgery.





Information Strategy for health and social care 2012

- transform how info is used across system
- ‘Digital first’ approach
- access to information through single portal
 - curation vs creation
- access to health records online by 2015

Taking the hassle out of healthcare

Access to good information is an important part of making sure people stay healthy and get the best care. By making it easier for you to look at and share your health and care records, you will be able to take more control of your own care, and work with professionals to make sure that there is 'no decision about me without me'.



1. Accessing your **GP records online** will give you more control over your care



2. **Booking appointments** will be quicker and easier when you can do it online



3. You'll need **fewer phone calls** when you can communicate with professional teams electronically



4. You'll have **less paperwork** in your life when your healthcare letters are available online



5. You'll know where to go for health and care information when there is **one trusted website**



6. Services will do more to **offer you support** to use and understand information if and when you need it



7. You won't have to repeat yourself when your **information is shared** between health and care professionals



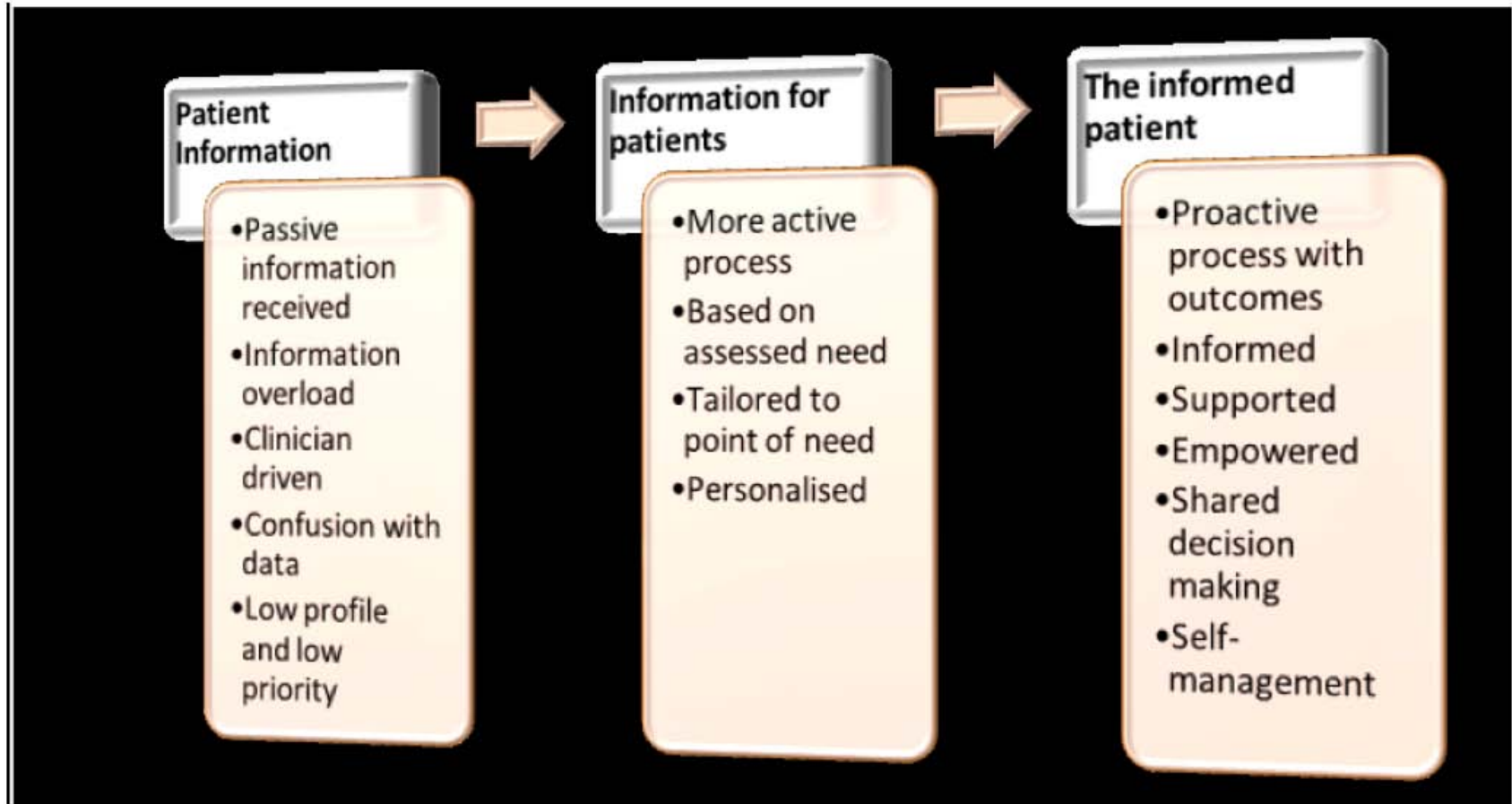
8. You'll be confident that your **feedback is being listened to** and helping to improve services



9. You will have more information to help you **choose the best services** and treatments for you



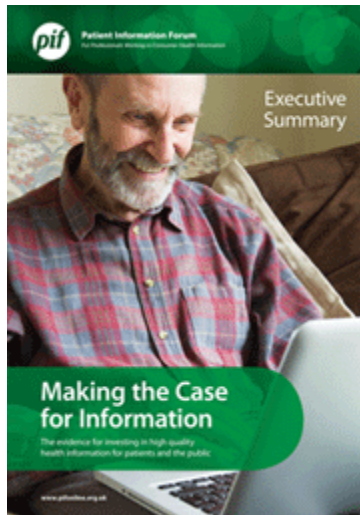
Evolution of patient information





Making the case for information

Patient Information Forum
(www.pifonline.org.uk)



- Consumer health info:
 - Benefits of providing
 - Harms of not providing

What works

- One size does not fit all
- Quality is paramount
- Info must be converted into knowledge
- Written info aids recall and understanding
- Info needs change over time
- Simpler materials address health literacy
- Websites are not the only answer

What works

- Patients need support to help them access, understand & act on info
- Info is part of a broader communication
- Active support has to accompany info

‘It is an essential service in its own right and its provision cannot be left to chance.’



Information Standard

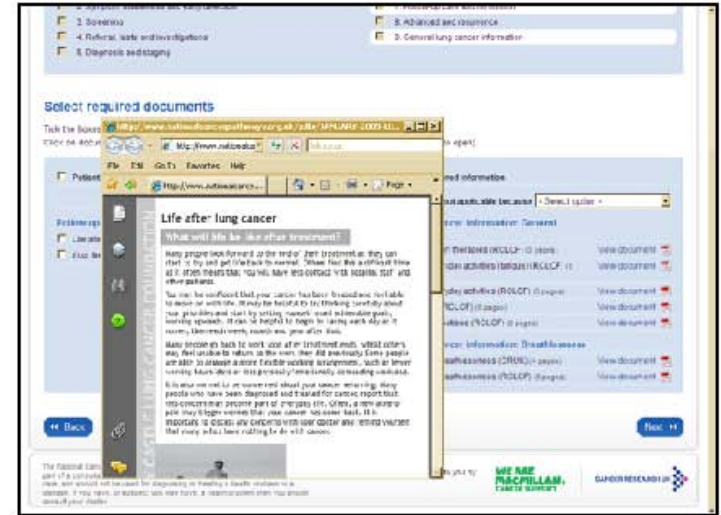


- Accreditation programme which reviews the process used to create and develop high quality written health information in England
- <http://www.theinformationstandard.org/>

Information Prescription

“An Information Prescription is a source of personalised information that lays out clearly and simply the salient points about an individual’s consultation with a healthcare professional about their diagnosis, treatment and/or care plan ..”

Cancer Backup 2007



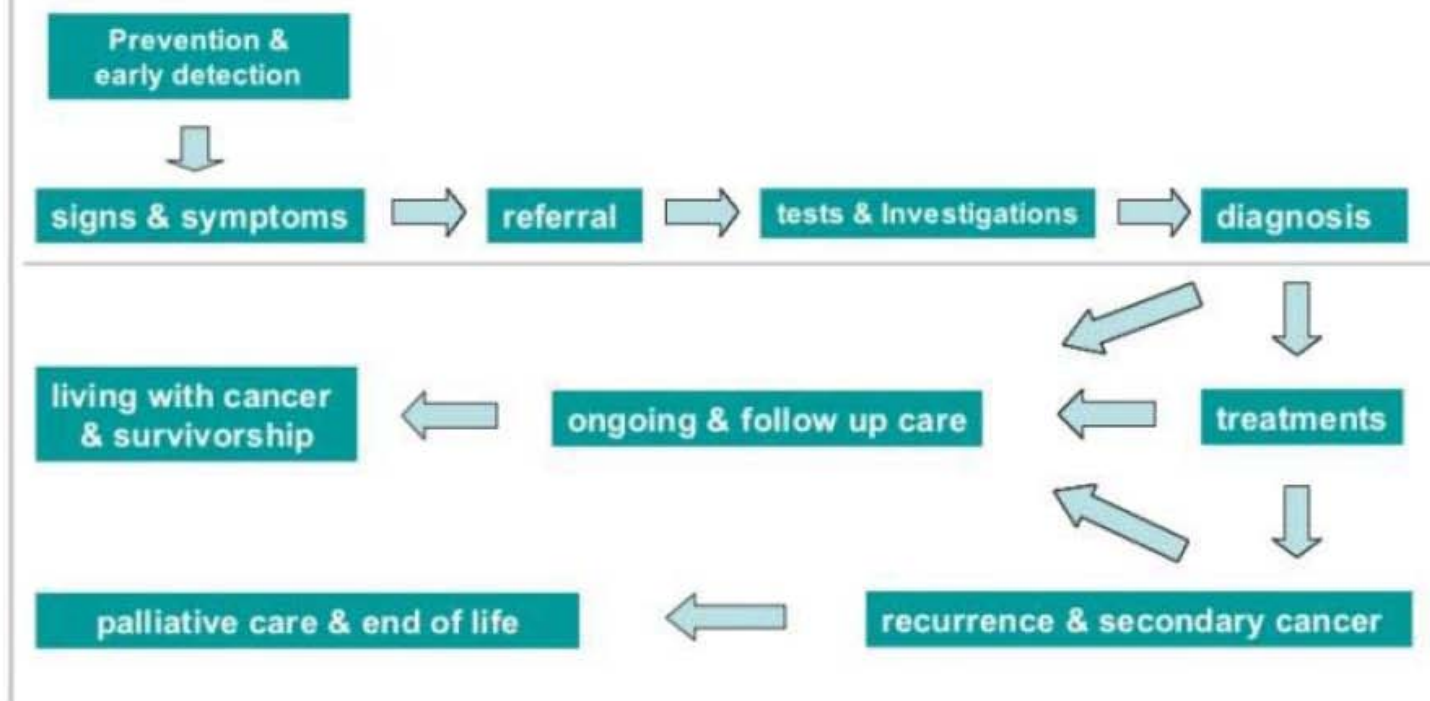


Information issues

- Variable quality of content on offer
- Booklets describing whole journey – overwhelming
- Duplication of content
- Lack of information on non-medical areas (financial and emotional support)
- Lack of consistency in what was given out

National Cancer Information pathway

(Key information points)



Information Prescription Service

- Search by condition
- Search by treatment

www.nhs.uk/ips

The screenshot shows the NHS Choices Information Prescription Service (IPS) homepage. At the top, there's a search bar for NHS Choices and a 'Go' button. Below this, a blue header contains the 'IP information prescription service' logo and text: 'Easy access to reliable health information provided by NHS Choices and partners'. Navigation links include 'Home', 'About this service', 'Contact us', and 'Partner list'. The main content area is titled 'Create an information prescription' and features a form with two input fields: 'Condition or treatment' and 'Postcode/location (optional)'. A link for 'A-Z list of treatments & conditions' is positioned between the fields. Below the form is a checkbox for 'Save my location' and a 'START' button with a right arrow. At the bottom, a section titled 'Our partners:' lists several organizations: 'WE ARE MACMILLAN. CANCER SUPPORT', 'Marie Curie Cancer Care', 'CLIC Sargent Caring for Children with Cancer', 'Diabetes UK', and 'CANCER RESEARCH UK'. A link for 'Full partner list' is also present.

Different types of content:

- general material from NHS Choices encyclopaedia;
- more in depth content from specialist charity providers

NHS choices
Logged in as Ruth Carlyle

Search NHS Choices **Search >**
[Prescribing history](#) [Manage your favourites](#) [Log out](#) [Your profile](#)

IP information prescription service
Quickly create a package of health information to print, email or save
[About this service](#) | [Contact us](#) | [Partner list](#)

Create an information prescription for **Bowel cancer**


[Print a blank form to fill in on paper](#)

To view PDF leaflets on this page [download Adobe Reader](#)

[Reset form](#)

Select your options:

- ▶ Basic NHS information about Bowel cancer [Show](#)
- ▶ Specialist information from our charity partners about Bowel cancer [Show](#)
- ▶ Local information about Bowel cancer [Show](#)
- ▶ Directory information [Show](#)
- ▶ Add personalised cover note [Show](#)

[Create information prescription](#) 

[Print a blank form to fill in on paper](#)

In depth content
categorised by stage
of pathway and
available to preview
or add to
prescription.

Includes written and
audio visual content

The screenshot shows a web browser window with the IP Information Prescription Service interface. The header includes the IP logo and the text 'information prescription service'. A sub-header reads 'Create an information prescription for Bowel cancer'. Below this, there are links to 'Print a blank form to fill in on paper' and 'Reset form'. The main content area is titled 'Select your options:' and contains several expandable sections: 'Basic NHS information about Bowel cancer', 'Specialist information from our charity partners about Bowel cancer', 'Prevention and risk factors', 'Symptom awareness and early detection', 'Screening', 'Referral, tests and investigations', and 'Diagnosis and staging'. Each section has a 'Show' or 'Hide' button. Under the 'Diagnosis and staging' section, there is a list of resources with checkboxes, titles, sources, and 'Preview' links. The resources include: 'Understanding bowel cancer (RCUK 4 pages)' from Bowel Cancer UK; 'How bowel cancer is diagnosed MCS 8 pages' from Macmillan Cancer Support; 'Small bowel cancer CRUK 4 pages' from Cancer Research UK; 'Small bowel cancer (MCS 7 pages)' from Macmillan Cancer Support; 'Staging and grading of bowel cancer MCS 3 pages' from Macmillan Cancer Support; 'Blood tests CRUK 2 pages' from Cancer Research UK; and 'colonic stenting (BBC 2 pages)' from Beating Bowel Cancer. The bottom of the screen shows a Windows taskbar with various application icons and a system clock indicating 22:27 on 29/03/2014.

Smaller sections of text which can be selected as appropriate for summary print out for patient

(Optional)

I would particularly like to draw your attention to the following...

Add pre-prepared content supplied by Cancer Research UK and Macmillan Cancer Support

Tests for bowel cancer: Rectal examination

Tests for bowel cancer: Proctoscopy/sigmoidoscopy

Tests for bowel cancer: proctoscopy/sigmoidoscopy

Tests for bowel cancer: Colonoscopy

Tests for bowel cancer: Barium enema

Tests for bowel cancer: virtual colonoscopy (CT colonography)

Tests for bowel cancer: CEA blood test

Tests for bowel cancer: Chest x-ray

Tests for bowel cancer: Abdominal ultrasound

Tests for bowel cancer: MRI (magnetic resonance imaging) scan

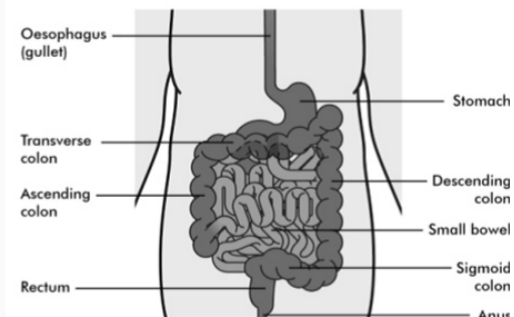
Tests for bowel cancer: PET (positron emission tomography) scan

Staging of bowel cancer

Dukes staging of bowel cancer

The large bowel (colon and rectum)

The bowel is part of our digestive system. It is divided into the small bowel and the large bowel. The large bowel is made up of the colon and rectum. Food is digested in the stomach and small bowel then moves into the colon where water is absorbed. The remaining waste matter, known as stools or faeces, passes into the rectum (back passage) and is held there until it is ready to be passed from the body through the anus as a bowel motion (stool). Close to the bowel are lymph nodes, also known as lymph glands, which are about the size of a baked bean. Most cancers start in the innermost lining of the bowel and develop from small growths called polyps.



Create information prescription

Print a blank form to fill in on paper

[NHS Choices for professionals](#) [Editorial policy](#) [Personal accounts](#) [News and updates](#)

Sources

- About the NHS:
<http://www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx>
- Info Strategy for NHS: The Power of Information:
<https://www.gov.uk/government/publications/giving-people-control-of-the-health-and-care-information-they-need>
- PIF 'Making Case for Info': www.pifonline.org.uk
- Information Standard:
<http://www.theinformationstandard.org/>
- Info Prescriptions: <http://www.nhs.uk/ips>

Thank You



<http://www.sxc.hu/photo/1238333>