

*Meeting the need for cancer
information
a UK perspective*

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Together we will beat cancer

What is the need ?

The voluntary sector has known for over 20 years that cancer patients and their families want information, as evidenced by the demand to charity funded cancer information services.

Jenkins, Fallowfield and Saul (2001) unequivocally established that cancer patients want information through a large well designed study.

In the UK many more studies have taken place but often small scale and specific to a cancer type or particular setting/circumstance.

Policy

Research, and lobbying from the voluntary sector over many years led to the importance of information being embedded in policy.

Policy

The NHS Cancer Plan 2000

“...Face to face communication needs to be backed up with high quality, accurate information that patients can return to in their own time...All NHS Trusts and networks are being required to make high quality information available to all cancer patients...”

Policy

Improving Supportive and Palliative Care for Adults with Cancer 2004

“Information needs to be of high quality to inform, support and reassure patients and carers. This means it must meet the needs of the target group and be evidence based, balanced, regularly updated, culturally sensitive, available in a variety of formats and composed in plain language. Service users and experts must be involved in design and development...”

Policy, the Choice Agenda

Better information, better choices, better health 2004

“People should

- Have access to accurate, high quality, comprehensive information delivered in the way they want;
- Have their personal information needs considered and discussed at every contact with healthcare professionals;
- Receive as much support as they want to access and understand information;
- Be empowered to ask questions and be involved as far as they want in making decisions about, for example, the benefits and risks of action and how these can be mitigated.”

Has policy driven change?

Yes. In 2004, provision of information had improved compared to 2000 (NAO 2005). But...

- In 2000 only 45% of patients reported receiving information. In 2004 this had improved to 61%, so still not everyone was receiving it.
- Provision varied between cancer type and geographical area. In 2004 69% of breast cancer patients had received information compared to only 55% of other cancers.
- 64% of patients outside London reported receiving information compared with 57% of patients treated in London.

Current policy

To address the current gaps in provision, the Cancer Reform Strategy (DH 2008) recommends.

- Introduction of National Cancer Information Pathways.
- Development of Cancer Information Prescriptions.

These recommendations have been influenced by lobbying from voluntary sector organisations, through individual organisations, partnership working and larger coalitions, such as the Coalition for Cancer Information.

National Information Pathways

Developed by asking cancer service providers what information materials they give at specific points on the cancer journey. Often these materials are booklets, factsheets or electronic resources produced by cancer charities.

Information Prescriptions

- Facilitate tailoring information to individual need.
- Pilots in the NHS are testing various delivery models.
- Cancer Research UK, Macmillan/Cancerbackup developing an on line tool for delivering highly individualised information prescriptions.

Information Prescriptions and the National pathways

These two projects are coming together, with the Cancer Research UK, Macmillan/Cancerbackup tool being used to deliver information prescriptions and the National Pathways.

The first phase of the tool will deliver the pathways and is currently being piloted.

The tool helps health professionals select and source PDF versions of existing information materials from a variety of sources

Information Prescriptions and the National pathways

National cancer information pathways

NHS
National Cancer Action Team

1 Cancer type 2 Key information point 3 All cancer information 4 Confirm ? Help

Welcome to the pilot national cancer information pathways system.

Welcome to the pilot National Cancer Information Pathways System.

The pilot system is part of a wider national cancer patient information initiative, which builds on work undertaken by cancer networks to map patient information to ensure coordinated patient information.

This pilot site provides health professionals with a central resource to access a wide range of information to support people affected by cancer. It includes a wide range of content provided by a range of national cancer charities.

This pilot has been designed to find out whether health professionals find this a useful way to deliver coordinated national core information to patients. This initiative is identified in the Cancer Reform Strategy and is being led by the National Cancer Action Team. The system has been developed in partnership with Cancer Research UK and Macmillan Cancer Support.

1 Select cancer type

- Bowel Cancer
- Breast Cancer
- Prostate Cancer
- Gynaecological cancers - cervix
- Gynaecological cancers - ovary
- Gynaecological cancers - vagina
- Gynaecological cancers - vulva
- Gynaecological cancers - womb

Can't find the cancer type you're looking for?

Next >>

The National Cancer Information Pathways System is designed to be used as part of a consultation with a health professional. It is not a substitute for medical care, and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem then you should consult your Doctor

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Information Prescriptions and the National pathways

National cancer information pathways

NHS
National Cancer Action Team

1 Cancer type 2 Key information point 3 All cancer information 4 Confirm ? Help

2 Key information point


You can only select one option

- 1. Prevention and risk factors
- 2. Symptom awareness and early detection
- 3. Screening
- 4. Referral, tests and investigations
- 5. Diagnosis and staging
- 6. Treatments
- 7. Follow-up care and remission
- 8. Advanced and recurrence
- 9. Palliative care and end of life
- 10. General bowel cancer information

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Select required documents

Click on document icon to view in a new window (please note, some documents may take some time to open).

<input type="checkbox"/> Patient given paper booklet(s)	<input type="checkbox"/> Patient declined information
Referral, tests and investigations: general information	Possible tests
<input type="checkbox"/> Examining the bowel (4 pages) View document	<input type="checkbox"/> Barium x-ray (3 pages) View document
<input type="checkbox"/> Tests for bowel cancer (2 pages) View document	

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Statutory information provision is only part of the story

Charity based, non NHS information services in the UK continue to experience increasing demand in spite of the improvements in information provision within the NHS.

- The CancerHelp UK Website has over 1 million unique users per month.
- Cancer Research UK's helpline and email service has seen a steady over all increase in enquiries, currently responding to between 10,000 and 10,500 enquiries per year.
- Cancerbackup responded to 37,883 telephone and email enquiries in 07/08.

The growth in web based services and user generated content

At Cancer Research UK we are seeing a constant increase in use of our patient information website CancerHelpUK.

We saw steady increases in requests for information by email until we took measures to moderate this to help manage demand.

Breast Cancer Care, has one of the longest established web based cancer forums in the UK. In 2007/8 they had 97,000 new posts on their forum and 5,800 new registered users.

Cancer Research UK's forum is seeing a steady increase in activity since its launch in early summer, with 359 registered users, 106 new threads and 715 new messages posted, and 6138 unique visitors to the site.

User generated content V “expert” information

- Is there a tension between the collective “wisdom” of user generated content and professionally produced evidence based cancer information?
- What are the implications for professionals in providing different channels for people to access/share information?
- What legal and ethical challenges may emerge when professionals moderate forums and enter users web space to provide answers to questions?
- Will we see a swing back to the use of “expert” information as social networking and bookmarking sites develop?
- How do we anticipate and respond to the ever changing environment of the web?

References

- Breast cancer Care (2008) Unpublished Statistics
- Cancerbackup (2008) Unpublished Statistics
- Cancer Research UK (2008)
- Department of Health (2000). The NHS Cancer Plan
- Department of Health (2004) Better Information, Better Choices, Better Health
- Department of Health (2007) Cancer Reform Strategy
- Jenkins V, Fallowfield L, Saul J.(2001) Information Needs of Patients with Cancer: Results from a large study in cancer centres. British Journal of Cancer 84, 48-51
- National Institute for Health and Clinical Excellence (2004). Improving Supportive and Palliative Care for Adults with Cancer
- National Audit Office (2005) The NHS Cancer Plan: A Progress Report
- National Audit Office (2005) Tackling Cancer: Improving the Patient Journey