



# MANAGING CANCER INFORMATION MATERIALS

A toolkit for cancer information  
and support service managers

4<sup>th</sup> edition

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MACMILLAN.  
CANCER SUPPORT**



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# FOREWORD

**'Cancer affects everyone differently, so it's vital that support is tailored to the individual and their unique needs.'**

**John Galfin, Cancer Information and Support Specialist**

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical and financial support and push for better cancer care.

Macmillan's cancer information services work towards this vision by ensuring that people affected by cancer have access to high-quality, comprehensive and appropriate information and support. We believe that information and skilled communication are an essential part of good cancer care. High-quality information should be provided as part of a supportive process that is tailored to the individual's needs at a given point in time.

The *Managing cancer information materials* toolkit helps managers of cancer information and support services to:

- identify the cancer information needs of people in their local community
- decide on appropriate roles for the service
- ensure that resources are accessible to the local community
- choose information resources that are relevant to people affected by cancer, including families and carers
- make optimal use of nationally-provided information resources
- set up and manage information systems so that resources can be located when needed, in a format that suits the individual
- keep information resources up-to-date
- assess how well they are doing and use this information for decision-making and planning
- work in ways that meet strategic quality goals for all Macmillan services.

Macmillan has also developed a set of standards called *Macmillan Quality in Information and Support Services (MQulSS)* to provide guidance on good practice in cancer information and support services. It sets standards of practice in planning; governance; user focus; leadership; managing people; learning and development; managing money and resources; promotion; working with others; and monitoring and evaluation.

The standards complement this toolkit and can be used to help develop new services, and achieve and maintain good-quality in existing services. Where the information in the toolkit applies to one or more of the standards, it is indicated alongside the text.

We hope that *Managing cancer information materials* will help you to provide well-planned information services safely, efficiently and effectively.



**Steven Wibberley**

Head of Information and Financial Support  
Macmillan Cancer Support  
November 2011



# INTRODUCTION

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# ROLE OF INFORMATION MATERIALS

**Information materials may be in print, audiovisual or electronic formats. People living with cancer have told Macmillan that they need to receive information, including information materials, within a supportive environment from skilled staff and volunteers.<sup>1</sup>**

People diagnosed with cancer and those close to them also need emotional support and practical help. Providing access to information materials is therefore just one aspect of the role of a cancer information and support service.

In order to provide information materials effectively, service providers need to:

- identify information needs
- ensure accessibility
- choose high-quality information materials
- manage systems so information can be located easily
- provide cancer information in a supportive manner
- know how to develop information materials if no appropriate resources exist.

Producing information materials is a significant undertaking and it isn't usually necessary because of the amount of high-quality local and national materials already available.

*Managing cancer information materials* provides practical guidance on these issues. While it has been designed to address concerns around managing cancer information materials, the content is also applicable to broader health information services.

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## Reference

<sup>1</sup> British Market Research Bureau. *Review of Macmillan Cancer Information and Support Services*. 2003. London, BMRB.

**For further information, contact the Information and Financial Support team on 020 7840 7829 or email [infomanager@macmillan.org.uk](mailto:infomanager@macmillan.org.uk)**

# CANCER POLICY CONTEXT

**Cancer information services don't work in isolation, so it's essential to be aware of the wider environment that your team is operating in.**

Health policy may change rapidly and sometimes unpredictably over the next few months and even years. This section of the guide paints the big picture, but you will need to keep up-to-date (see below).

## Check regularly for updates

Making a quick check online, perhaps once a month, will help you stay current. A visit to one or two of these websites will give you a good overview.

### Department of Health

[www.dh.gov.uk](http://www.dh.gov.uk)

### Health and Social Care in Northern Ireland (HSC)

[www.healthandcareni.co.uk](http://www.healthandcareni.co.uk)

### Macmillan Cancer Support (campaigns section)

[www.macmillan.org.uk/campaigns](http://www.macmillan.org.uk/campaigns)

### Public Health Wales

[www.wales.nhs.uk/sitesplus/888](http://www.wales.nhs.uk/sitesplus/888)

### Scotland's Health on the Web (SHOW)

[www.show.scot.nhs.uk](http://www.show.scot.nhs.uk)

Policies around health, cancer and patient information are continually evolving across the four nations. Each has a different approach, based on increasingly different national priorities and strategies.

## Scotland

The development of patient information services in Scotland has been driven by three main policy initiatives:

- **Better Health, Better Care (2007)** is the overarching strategy for NHS Scotland. It emphasises health improvement, tackling health inequality and improving the quality of healthcare. The policy encourages patient and carer empowerment through ‘accessible, plain, clear, appropriate and timely information.’
- **The Healthcare Quality Strategy for NHS Scotland (2010)** aims ‘to ensure that everybody has access to the advice and information they need, when they need it.’
- **Better Cancer Care, An Action Plan (2008)** is the Scottish cancer strategy. An important part of this policy is close working with the voluntary sector to provide support, information and advice to people affected by cancer.

NHS Scotland aims to have a joined-up approach to cancer information using three main channels of communication:

- face-to-face consultations
- telephone conversations
- online resources.

The hub for initiatives and quality standards is called **NHS Inform** – the national health information service for Scotland. It’s hosted by NHS 24 and is a partnership between:

- the Scottish Government Health Directorates
- NHS 24 (national helpline and web service)
- NHS Education for Scotland (NES)
- the voluntary sector, including Macmillan.

NHS Inform aims to provide ‘a coordinated approach and a single source of quality-assured health information for the public in Scotland.’<sup>1</sup> The NHS Inform website – **nhsinform.co.uk** – provides basic information about cancer care and specific cancer types.

Patients looking for more detailed information can visit The Knowledge Network website. It includes information and learning resources, a personal web space and online community tools. It’s also a useful resource for health and social care professionals and cancer information managers. Visit **knowledge.scot.nhs.uk**

Managed clinical networks help inform the commissioning and provision of services in Scotland. They also play a key role in the delivery of high-quality patient information.<sup>2-4</sup>

## Wales

There is currently no overarching national policy that commits the Welsh government to provide appropriate information and support to people affected by cancer throughout their cancer journey. However, in the run up to the 2011 National Assembly for Wales elections, Macmillan lobbied all political parties to include commitments in their manifestos relating to information and support for people affected by cancer.

Welsh Labour, which went on to win the election and form a government, included the following commitment in their manifesto: ‘... in our next Assembly term, Welsh Labour will: Give every person diagnosed with cancer access to information to help them with the financial, emotional and practical impact of cancer’.

Macmillan is working in partnership with the government and Public Health Wales to build on this commitment by funding a strategic cancer information and support project for Wales. The aim is to ensure that all people with cancer in Wales have access to personalised cancer information. This will be delivered in accordance with a nationally agreed vision and framework for personalised patient information in Wales.

Several broader national health policy statements refer to information and support, including:

- ***Designed To Tackle Cancer in Wales: Strategic Framework (2008–11)***
- ***Improving supporting and palliative care guidance for adults with cancer (NICE, 2004)***
- ***National Cancer Standards***
- ***Designed to Improve Health and the Management of Chronic Conditions in Wales (2007)***
- ***Setting the Direction: Primary & Community Services Strategic Delivery Programme (2010)***
- ***Rural Health Plan (2009).***

The government is currently developing the third phase of ***Designed to Tackle Cancer in Wales (2011–2015)*** and Macmillan is working with it to ensure that the manifesto commitment around information and support is taken up and reinforced within this national policy document.



## England

England has strong and well-established policy drivers for both cancer care and patient information.

***Improving outcomes: a strategy for cancer (2010)***, which updates the ***Cancer Reform Strategy (2007)***, states that 'accurate, tailored, timely and accessible information is vital to providing a good patient and carer experience.'

The strategy acknowledges the work that Macmillan and others have done to develop information prescriptions, recognising that they 'guide people to relevant and reliable sources of information to allow them to feel more in control, better able to manage their condition and maintain their independence.'

It follows the report of the National Cancer Patient Experience Survey Programme 2010, which found that 34% of people with cancer were not given written information about their cancer at the time of diagnosis.<sup>5</sup>

The broader agenda on health information is being shaped by the NHS white paper ***Equity and excellence: Liberating the NHS (2010)***. The consultation document, ***Liberating the NHS: An information Revolution (2010)*** describes the government's vision for information. This includes proposals to make facts and figures available to patients via information intermediaries – that is, independent third parties who interpret and present raw data supplied by government.

At present, the National Cancer Action Team leads on implementation of cancer policy nationally. Local implementation of national policy is currently coordinated by 28 cancer networks. Local information centre managers will need to work closely with cancer networks to ensure Macmillan and local NHS services are integrated.

## Northern Ireland

**Cancer prevention, treatment and care (2011)** includes several standards on access to information. The framework includes targets for delivery of cancer information pathways and defines key points for delivery at different stages of the patient's journey.

Developments are taking place to ensure that each hospital providing NHS cancer services has a cancer information and support centre, and that these are linked within the Northern Ireland Cancer Network (NiCAN).

Information that is tailored to individual needs is a feature of **Living with Long Term Conditions – a policy framework**. A consultation period ran from February–June 2011.

## Macmillan across the four nations

The development of cancer services and information and support policies takes place separately in each of the four nations and Macmillan has teams working in each nation that stay in touch with each of the devolved governments. We also bring together senior NHS staff and civil servants with a health information role to ensure that best practice is shared across the UK nations.

We are in a unique position to enable shared learning across the UK and do our best to make the most of this opportunity for the benefit of NHS services, people with cancer and their families.

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### References

<sup>1</sup> NHS Inform. <http://www.nhsinform.co.uk/about-us.aspx> (accessed 21 October 2011).

<sup>2</sup> Southeast Scotland Cancer Network (SCAN). <http://www.scan.scot.nhs.uk/> (accessed 21 October 2011).

<sup>3</sup> North of Scotland Cancer Network (NOSCAN). <http://www.noscan.scot.nhs.uk/> (accessed 21 October 2011).

<sup>4</sup> West of Scotland Cancer Information Network (WoSCAN). <http://www.woscan.scot.nhs.uk/> (accessed 21 October 2011).

<sup>5</sup> Department of Health. *National Cancer Patient Experience Survey Programme – 2010: national survey report*. 2010. DH.



# USING THIS GUIDE

Although you may choose to read this guide from cover to cover, it has been designed to help you to find information when you need to refer to it.

## Following the format

The content is divided into six main sections:

- 1 Identifying information needs
- 2 Ensuring accessibility
- 3 Choosing information materials
- 4 Managing information materials
- 5 Providing cancer information
- 6 Developing new resources.

Each section has been written to a standard format, starting with a navigation guide to tell you which topics follow. At the end of each section there is a checklist and a list of suggested further reading.

## Contents and index

The topics within each section are listed at the beginning. A full list of issues covered within the text is can be found in the index.

## The toolkit as a starting point

This toolkit is intended as a starting point for people managing information materials as part of a cancer information and support service. Within the guide, you will find tips, suggested further information and sources of help.

## Keeping up-to-date

It's a good idea to check for updated information regularly at [macmillan.org.uk/learnzone](https://macmillan.org.uk/learnzone) (under 'Health and Social Care Professionals' then 'Macmillan information resources'). We will also alert you of any updates in the monthly e-newsletter, *Inside information*. If you don't currently receive this, please email [cissinfo@macmillan.org.uk](mailto:cissinfo@macmillan.org.uk) to be added to the mailing list.

**If you need additional help to manage your information collection, contact the Information and Financial Support team on 020 7840 7829 or email [infomanager@macmillan.org.uk](mailto:infomanager@macmillan.org.uk)**



# IDENTIFYING INFORMATION NEEDS

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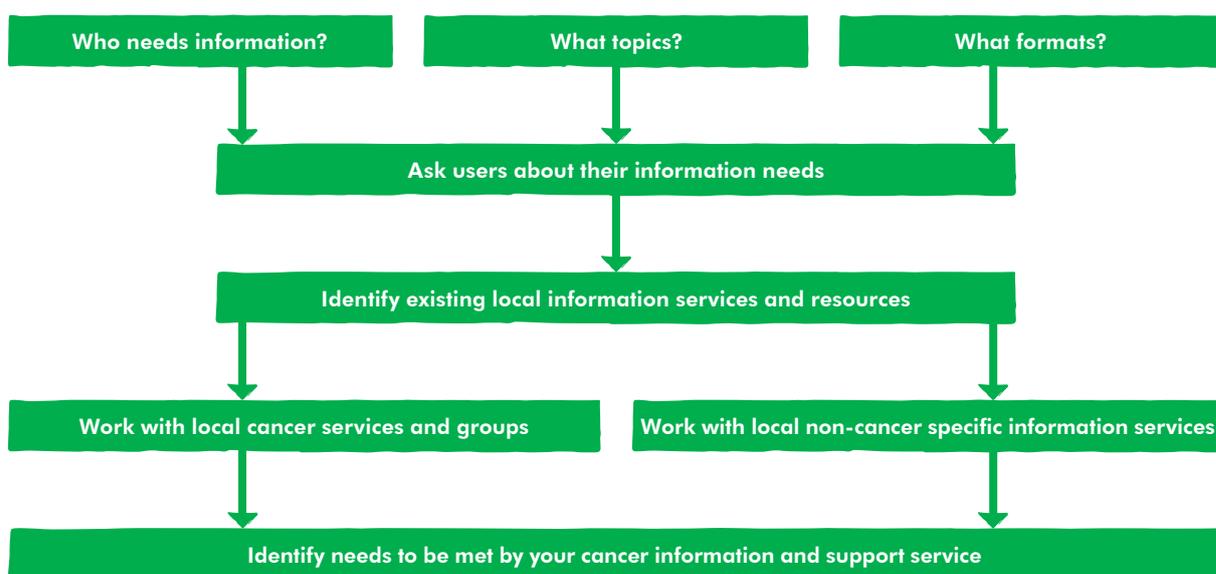


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# IDENTIFYING NEEDS TO BE MET BY YOUR SERVICE

**'Everybody's needs are different. The key to helping each person individually is to listen carefully and use the Macmillan resources to help meet their needs.'**

**Penny Jarvis, Health Information Facilitator**



## Value of identifying your users' needs

Each cancer information and support service is unique. The topics, formats and arrangement of information materials will be most effective if they reflect the particular needs of people (users) in your local community.

Assessing the needs of potential users should take place during service planning. It's also important for established services to check that needs haven't changed.

**See 'Quality area 4: user-centred service – indicators 1, 2 and 4' of MQiSS in appendix 1.**

Good signage and positive associations with the Macmillan Cancer Support logo will attract a range of users in most locations, including:

- people living with cancer (patients)
- family members and friends (some of whom may be carers)
- people who have had cancer (who may have finished treatment or been 'cured')
- health and social care staff (who may want information for their own use or to supply to people affected by cancer in their care)
- people with symptoms they suspect may be caused by cancer – sometimes referred to as 'the worried well'
- people who want to reduce their risk of developing cancer (who may be prompted by cancer-related items in the news).

The services you provide to people affected by cancer need to be considered in context. It's important to establish what other service providers exist locally and nationally. This section outlines key methods for identifying local needs and mapping existing services to help you identify the topics and formats for information materials you need to hold.

**See 'Quality area 10: working with others – indicators 1 and 2' of *MQulSS* in appendix 1.**

# METHODS FOR INFORMATION NEEDS ASSESSMENT

One of the important strengths of your cancer information service is that it can be tailored to meet the needs of local people. Therefore, it's vital to assess those needs in a systematic way when a service is launched. This will ensure you are providing information that is suitable for your local users.

See 'Quality area 4: user-centred service – indicators 1, 2 and 3' of *MQuISS* in appendix 1.

Assessing the needs of your service users is not a one-off exercise. You should also review these needs as part of the ongoing monitoring and evaluation of your service.

See 'Quality area 11: monitoring and evaluation – indicators 3 and 5' of *MQuISS* in appendix 1.

Some possible methods are suggested below but it's not a prescriptive list. Every centre has its own circumstances and its own approach, so choose the ideas that will work best for your team and service users.

## Assessing local information needs

Consider what you need to know and the best methods for finding this information. As a basic starting point, you can consider these questions:

- **Who** needs information about cancer and support services from my service?
- **Who** should guide the person through their information choices?
- **What** type of information and support do they need?
- **What** do they expect of the materials the service provides?
- **What** formats/languages are accessible to them?
- **What** level of detail do they need?
- **Why** are they looking for information?
- **When** do they need the information?\*
- **Where** do they want to access the information?
- **How** do they find information?
- **How** will they use the information?

See 'Quality area 4: user-centred service – indicators 1 and 2' of *MQuISS* in appendix 1.



### Reference

\* This is an important question as the National cancer patient information pathways ([see page 107](#)) emphasise providing the information that is most valuable to the person at a given point in time, for example at diagnosis, during and after treatment.

Resources may be limited, so think about ways to make best use of what is available to you. Make sure you are familiar with local networks and information services so that you complement, rather than duplicate existing services ([see page 22](#) for more details):

- Your **local NHS cancer services** will have an understanding of local needs and expertise in assessing them.
- Public health responsibility is moving to **local authorities** so they are good potential partners for joint working. The local authority should also be able to help build up a profile of your population.
- Talk to **other local charities** in health and social care – even if they don't specialise in cancer there may be opportunities for joint working and mutual support.

## Use local cancer statistics

To build up a picture of your local population, you can find a wealth of useful information on cancer registry websites.

For England, statistics are available from the eight regional cancer registries (see opposite). Regional statistics for Wales, Scotland and Northern Ireland are provided by national agencies (see below).

In addition, the National Cancer Intelligence Network (NCIN) hosts a number of data tools and publishes national and regional level data on incidence, mortality, survival, prevalence, plus cancer-specific analyses and briefings.

### Find statistics

#### National Cancer Intelligence Network

[www.ncin.org.uk/publications/default.aspx](http://www.ncin.org.uk/publications/default.aspx)

#### UK Association of Cancer Registries

[www.ukacr.org](http://www.ukacr.org)

#### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

[www.wales.nhs.uk/sites3/home.cfm?OrgID=242](http://www.wales.nhs.uk/sites3/home.cfm?OrgID=242)

#### NHS Scotland Information Services Division

[www.isdscotland.org](http://www.isdscotland.org)

#### Northern Ireland Cancer Registry

[www.qub.ac.uk/research-centres/nicr](http://www.qub.ac.uk/research-centres/nicr)

## England: regional cancer statistics

### Eastern Cancer Registration and Information Centre

[www.ecric.nhs.uk](http://www.ecric.nhs.uk)

### North West Cancer Intelligence Service

[www.nwcis.nhs.uk](http://www.nwcis.nhs.uk)

### Northern and Yorkshire Cancer Registry and Information Service

[www.nycris.nhs.uk](http://www.nycris.nhs.uk)

### Oxford Cancer Intelligence Unit

[www.ociu.nhs.uk](http://www.ociu.nhs.uk)

### South West Cancer Intelligence Service (South West Public Health Observatory)

[www.swpho.nhs.uk/cis](http://www.swpho.nhs.uk/cis)

### Thames Cancer Registry

[www.thames-cancer-reg.org.uk/](http://www.thames-cancer-reg.org.uk/)

### Trent Cancer Registry (East Midlands Public Health Observatory)

[www.empho.org.uk/tcr/aboutus.aspx](http://www.empho.org.uk/tcr/aboutus.aspx)

### West Midlands Cancer Intelligence Unit

[www.wmpho.org.uk/wmciu](http://www.wmpho.org.uk/wmciu)

## Choose your methods

You can select from several simple methods to assess information needs or collect user feedback, depending on what you need to find out:

- **Qualitative** methods (non-numerical) can help you answer the 'how' and 'why' questions in a more in-depth way from a smaller number of people. Some examples are focus groups and interviews.
- **Quantitative** methods (gathering statistics and figures from a larger number of people) can help you answer questions like 'how many' people want something, 'how large' the unmet need is or 'how important' an issue is to local people. A questionnaire is a commonly used quantitative tool.

### Holding a resource day

Organising a resource day allows you to consult with a group of users and seek their views on the materials you provide. It also helps to publicise your services.

You could use several information-gathering techniques on the day, such as focus groups or questionnaires (see below).

If you hold your resource day prior to opening a new centre, select the venue in consultation with potential users. They may prefer a place outside the healthcare environment.

If your centre is already established, try fun activities like a quiz or treasure hunt, challenging people to find specified information. This will give you some idea of how user-friendly your system is. You can also ask them to rate the usefulness of the information on offer, where the gaps are and what kind of support they would like from staff.

### Focus groups

A focus group gathers people together to consider a specific issue. Aim to recruit a cross-section of service users. If you feel that some people may not be happy speaking out in front of others (for example, some men may not wish to speak about their health fears in front of women), organise separate sessions. Providing a pleasant environment, refreshments, and reimbursing travel costs and caring expenses encourages participation and shows participants they are valued.

To develop a full analysis of a focus group's discussion, you will need a record of what was said, but reassure participants that their comments won't be attributed to them personally. Someone will need to take notes and type them out.

If you don't have the time or staff to do this, you could ask participants to write down any issues – perhaps on a set of blank cards – and then ask them to rank their importance with a vote. This is sometimes known as the 'pin board' technique. It's good for encouraging participation and it provides a ready-made record to help you write up your findings.

### Interviews

Like focus groups, individual interviews can be a useful technique for discovering how people feel about information materials and services. For qualitative results, you can keep it more informal and ask open-ended questions that allow a free response, but you should have a list of broad questions/areas that you want to ask people about.

For quantitative results, you will need to carry out structured interviews. This means you use the same questions for every person. The questions must also have a limited number of possible answers. This usually means using only yes/no or multiple-choice questions.

Interviews are a useful technique, but they can be time-consuming and costly. If you just have specific questions about information materials, rather than broader issues to discuss, consider using other techniques first.

## Questionnaires and patient surveys

Asking patients or service users to answer a list of written questions can give you both qualitative and quantitative information. Two options are:

- a questionnaire offered to existing service users
- a patient survey offered in hospital outpatient clinics or wards to assess needs and perceptions/views beyond your users.

You may wish to conduct focus groups or interviews first to develop the questions for your survey (see above). You could also work with user groups or self-help groups to identify issues that should be covered.

Consider simple ways to encourage continual assessment. You could set out a suggestions box or a comments book. Each time you give out information materials, you could slip a short questionnaire inside the cover.

Bear in mind that some people may have difficulty in using information in a written format, for example if they have a low level of literacy or poor vision, and they may be reluctant to mention these barriers. These people will have less access to information through other routes so they are an important client group. Make sure you provide alternatives so everyone's needs can be met. (**See section 2** for more information about accessibility).

**See 'Quality area 4: user-centred service – indicator 3' of *MQuISS* in appendix 1.**

## Do you need approval?

Some surveys and consultations involving patients require prior approval from a research ethics committee (REC). Whether you need ethical approval or not will depend on the kind of research/scoping work you want to do. If you're unsure, you can check with your local REC. You'll find contact details at [nres.npsa.nhs.uk/contacts/nres-committee-directory](https://nres.npsa.nhs.uk/contacts/nres-committee-directory)

Macmillan's Intelligence and Research team is also happy to give you advice. Please email [iandrenquiries@macmillan.org.uk](mailto:iandrenquiries@macmillan.org.uk) or call **0808 808 00 00** and ask to speak to a member of the team.

# IDENTIFYING LOCAL INFORMATION AND SUPPORT

**The cancer information and support service you are developing doesn't exist in isolation. Knowing what exists locally will help you link to other services and avoid inappropriate duplication of resources.**

See 'Quality area 10: working with others – indicators 1 and 10' of **MQulSS** in appendix 1.

## Working with cancer networks

The NHS has established a multidisciplinary cancer network in your region to advise on the development of cancer care. The cancer network is likely to have carried out an audit of existing services and the cancer information materials used locally. The cancer network should also be able to advise on local implementation of National cancer patient information pathways, including guidance on what information people can be offered at each stage in their experience of cancer.

Further information on the National cancer patient information pathways is included in on **page 111–112** of this toolkit.

## Working with local support groups

Local self-help and support groups for people affected by cancer are a key part of the local support network. Members of the groups may be able to help you to assess local information needs. You can search for support groups at [macmillan.org.uk/supportgroups](http://macmillan.org.uk/supportgroups)

There are two main types of self-help or support group – those that are user led and those that are professionally led. However, the elements in the list below are not mutually exclusive and many groups will vary their format.

### Self-help groups

Usually self-help groups consist of people with cancer and their families who meet to support each other by sharing personal experiences. They may be affiliated to national organisations and may sometimes invite speakers. Contacting the chair of the committee or the coordinator of the group will help you to establish what they do and ways in which your service could help, such as providing access to information or a meeting room.

### Support groups

Most support groups are facilitated by users. A clinical nurse specialist or other health professional may set up the group and then hand over control of the meetings over to the group members. Some groups that refer to themselves as support groups are self-help groups. The facilitator may be happy to refer people to your service and to display information materials at meetings.

### Step programme groups

Step programme groups tend to be orientated around behaviour change, such as Alcoholics Anonymous. Although they are not usually cancer-specific, links with these groups can be an important part of the support for people with cancer and their families. For example, the diagnosis of lung cancer in a family member may prompt interest in smoking cessation groups.

### Self-management/expert patient programmes

These short courses help people with long-term health conditions to self-manage. They are often delivered by people who are themselves living with a long-term condition. Many are run by the Expert Patient Programme Community Interest Company ([expertpatients.co.uk](http://expertpatients.co.uk)) and Macmillan has developed a cancer-specific version called New Perspectives ([macmillan.org.uk/courses](http://macmillan.org.uk/courses)). Course facilitators may be happy to display information materials during the sessions.

## Working with local information services

### Public library services

People worried that they have a health problem or who know someone affected by cancer may go to a public library. Offering to help local libraries select information materials on cancer forms a supportive link, and helps them choose reliable, up-to-date information.

Macmillan publishes a core cancer book list that enables libraries to select books about cancer that are up-to-date, appropriate for their local populations and have been reviewed by people affected by cancer and health and social care professionals. Your central library will be able to advise you of the person responsible for health information stock selection in your area.

For a copy of the core cancer book list, contact the Information and Financial Support team on **020 7840 7829** or email [infomanager@macmillan.org.uk](mailto:infomanager@macmillan.org.uk)

### Citizens Advice

Living with cancer places pressure on all aspects of life. Visiting your local Citizens Advice may help to ensure that you are aware of the full range of local support so that you can refer people appropriately. You can search for your local office at [citizensadvice.org.uk](http://citizensadvice.org.uk)

### Local NHS services

Details of local health services are available through:

#### NHS Direct (England)

0845 4647  
[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

#### NHS Direct Wales

0845 4647  
[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

### NHS Choices

[www.nhs.uk](http://www.nhs.uk)

#### NHS24 (Scotland)

08454 24 24 24  
[www.nhs24.com](http://www.nhs24.com)

### Health and Social Care Northern Ireland

[www.n-i.nhs.uk/](http://www.n-i.nhs.uk/)



# IDENTIFYING THE ROLE OF YOUR SERVICE

As a service provider, you don't have to provide detailed information and long-term support on all aspects of living with cancer. Decide on the role(s) for your service, for each topic needed, in the context of resources available locally.

## Options for information and support services roles

Services provided (to be considered by topic)	Primary provider of information in the locality	One of several local services	Other specialist service available
Detailed information	✓	✓	
Basic information	✓	✓	✓
Referral address		✓	✓
One-to-one information and support	✓		
Sessional support from specialist, eg welfare rights adviser		✓	
Ongoing support	✓	✓	
Basic support		✓	✓

## Mapping needs against available services

Assessing the role for your service isn't an exact science. Mapping information needs against the local resources available will help you and your advisory group to identify possible roles for the service. This will inform the overall aim and operational policy for the service.

You could also consider mapping the local services against their availability. If a service is available only on one day a week or is inaccessible by public transport, this may have an impact on the level of information or support you need to provide.

## Deciding on the overall aim of your service

The overall aim of your service will determine the information materials you select and the services you provide. It's therefore important that you have a clear written statement of purpose as part of the operational policy you develop with the advisory group for the service. If you are clear about the purpose of the resources within the service, it will be easier to select appropriate information materials.

For guidance on developing an operation policy, please contact your Macmillan Development Manager. Visit [macmillan.org.uk/service-development-contacts](https://macmillan.org.uk/service-development-contacts) You can download an operational policy template at [macmillan.org.uk/learnzone](https://macmillan.org.uk/learnzone) (under 'Health and Social Care professionals' then 'Macmillan information resources')

See 'Quality area 1: planning' of *MQUISS* in appendix 1.

## Example of needs matched to the role for your service

Need	Possible role for your service
Cancer prevention	<p>Key role for community-based services. Keep a good stock of health promotion leaflets and stay up-to-date on website sources.</p> <p>Good resources also exist in the NHS, but distribution is patchy.</p>
Cancer treatment and side effects	<p>Primary provider, especially to fill the gap for families. Also provided by cancer specialists.</p>
Cancer types	<p>Role will vary according to local resources. Form links with clinical nurse specialists.</p> <p>See also National cancer patient information pathways where available.</p>
Using health services	<p>One of several providers, giving specific information on cancer services.</p> <p>Other providers include GPs, NHS Patient Advisory and Liaison Service (PALS), Citizens Advice, NHS Choices.</p>



Need	Possible role for your service
Financial support	<p>Provider of cancer-specific information. Refer to local Macmillan benefits advice service or Macmillan Support Line.</p> <p>Other providers include Citizens Advice, Department for Work and Pensions, Directgov website (NIDirect website in Northern Ireland).</p>
Caring	<p>Primary provider for cancer-specific information. Ensure links for two-way referrals with local carer organisations and NHS.</p> <p>Other providers include local branches of charities and carer support centres.</p>
Support for children	<p>Primary provider of information about cancer for children. Provide support and refer to support specifically for children.</p> <p>General support offered through after-school clubs.</p>
Relationships	<p>Primary provider of cancer-specific information. Provide ongoing support. If necessary, refer to counselling service and/or legal adviser.</p> <p>Relationship and family guidance available through Relate. Some local religious groups run retreats or counselling for couples and families.</p>
Loss and bereavement	<p>One of many sources of support and general printed information on loss.</p> <p>Other sources include Cruse Bereavement Care, Compassionate Friends, local hospices and religious groups offering support.</p>

Need	Possible role for your service
<p>Black and minority ethnic communities</p> <p><b>See 'Quality area 4: user-centred service – indicator 3' of MQulSS in appendix 1.</b></p>	<p>Primary provider of cancer-specific information, working with interpreter services.</p> <p>Provide audiovisual and print materials where available. See Macmillan's <i>Guide to BME cancer resources</i>.</p> <p>Provide advocacy and support to ensure better understanding of information.</p> <p>Other providers include the NHS cancer screening programme, which has information in a range of languages; interpreter services through NHS Direct and local community groups or charities for BME communities provide specific information and support.</p>
<p>Support for people with disabilities</p> <p><b>See 'Quality area 4: user-centred service – indicators 2 and 3' of MQulSS in appendix 1.</b></p>	<p>Primary provider of cancer-specific information. Provide information in non-print or 'easy read' formats. Ensure information displays accessible to people with a physical disability. Provide advocacy and support to ensure better understanding of information.</p> <p>Other providers include local branches of charities for people with disabilities, day centres and home respite care service.</p> <p><b>This list is not exhaustive.</b></p>

## Macmillan information resources

Macmillan produces over 200 booklets, leaflets and audiovisual materials for people affected by cancer. We also produce the *Cancer Factfile*, a CD-Rom containing over 350 fact sheets covering a wide range of cancer topics. To order any of these resources, visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call **0800 500 800**.



# CHECKLIST AND FURTHER READING

## Checklist

Ask users/potential users about their information needs



Contact local cancer network to find out about expectations for the role of the service within the network



Identify existing information and support services



Establish links with local cancer services and support groups



Establish links with local information services



Identify role for your cancer information and support service within existing local services



Develop overall aim and operational policy for service to meet local information needs



**See Appendix 1 for more details about setting up your service.**

## Further reading

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Wittmann E, Beaton C, Lewis WG, et al. Comparison of patients’ needs and doctors’ perceptions of information requirements related to a diagnosis of oesophageal or gastric cancer. *European Journal of Cancer Care*. 2010. Article first published online: doi: 10.1111/j.1365-2354.2009.01169.x.

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# 2

## ENSURING ACCESSIBILITY

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### In this section:

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# ACCESSIBILITY AND GOVERNMENT LEGISLATION

**'Our vision is of a health and social care system where equal access to and appropriate delivery of the best quality cancer care services are available to everyone living with and beyond cancer.'**

***Macmillan Inclusion Strategy (2009–2014)***

Accessibility of information materials needs to be considered in a number of different ways so that all communities and groups feel supported.

The cancer information centre itself needs to be physically accessible to people with mobility or visual problems. Space is needed for wheelchairs to be turned around and edges to steps or doorways need to be visibly marked for people with visual impairment. The information materials need to be arranged so that topics are clearly visible.

Some people will need information materials in specific formats or languages, or support to access information in other ways. In addition, the information relevant to people of different age groups, disabilities, ethnic background, gender, identity, religion or belief and sexual orientation. The information should also consider rarer cancers, the carer's perspective and socioeconomic factors.

Taking these elements into account will help ensure that the information you provide meets the needs of a greater diversity of people and helps Macmillan reach everyone affected by cancer.

**See 'Quality area 4: user-centred service – indicators 1, 2 and 3' of MQISS in appendix 1.**

## The Macmillan Quality Environment Mark

The Macmillan Quality Environment Mark (MQEM) is a quality standard used to assess various cancer care environments, including information and support centres. An award is offered to environments that meet the standards. **Accessibility** is one of the five core principles underpinning the MQEM and a number of criteria have been developed to promote the importance of accessibility to a cancer care environment. There are also a number of criteria pertaining to the accessibility of information for users of these environments. For the most up-to-date version of the MQEM standards, visit [macmillan.org.uk/mqem](http://macmillan.org.uk/mqem)

## The Equality Act 2010

People with cancer are legally protected from discrimination and harassment. In England, Scotland and Wales this is under the Equality Act 2010. The Disability Discrimination Act 1995 preceded the Equality Act and still applies in Northern Ireland. Under both pieces of legislation, someone who has, or has had, cancer cannot be discriminated against.

According to the Government Equalities Office, the Equality Act 2010, 'replaced previous anti-discrimination laws with a single act to make the law simpler and to remove inconsistencies. This makes the law easier for people to understand and comply with. The act also strengthened protection in some situations.'<sup>1</sup>

The act applies to your cancer information centre because you provide a service and facilities to the public. The act applies whether or not a fee is charged for services. This important legislation covers nine 'protected characteristics' including:<sup>1</sup>

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race (this includes ethnic or national origins, colour and nationality)
- religion or belief
- sex
- sexual orientation.

While it's important to respond to the requirements of legislation, it's also important to be aware of other issues that can have a negative impact on accessibility.

### The Equality Act 2010

You can find more information about the act from these websites:

#### Equality and Diversity Forum

[www.edf.org.uk](http://www.edf.org.uk)

#### Equality and Human Rights Commission

[www.equalityhumanrights.com/advice-and-guidance/new-equality-act-guidance](http://www.equalityhumanrights.com/advice-and-guidance/new-equality-act-guidance)

#### The Home Office

[www.homeoffice.gov.uk/equalities](http://www.homeoffice.gov.uk/equalities)

#### Macmillan Cancer Support

[www.macmillan.org.uk/work](http://www.macmillan.org.uk/work)

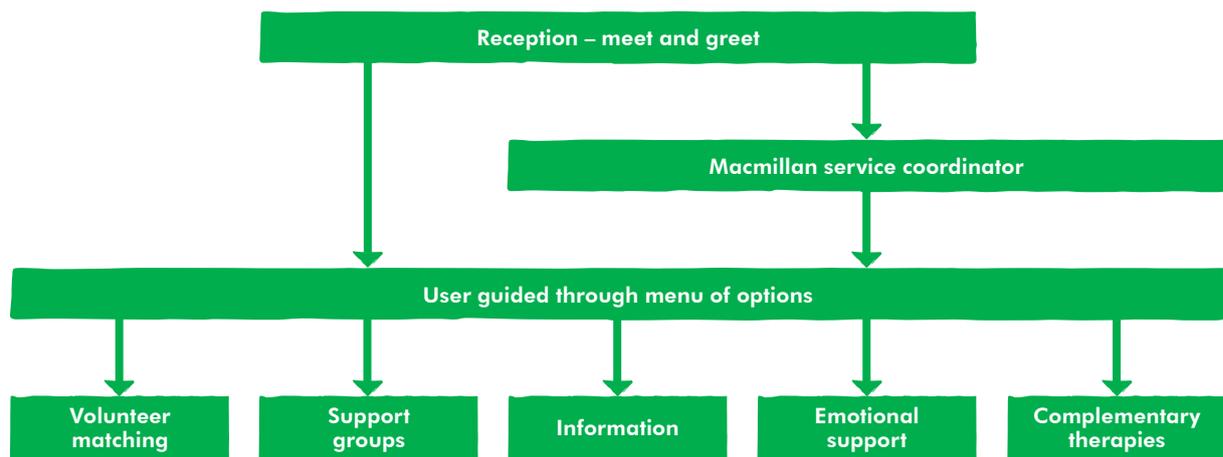
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### Reference

<sup>1</sup> Home Office. *Equality Act 2010*. <http://www.homeoffice.gov.uk/equalities/equality-act> (accessed 21 October 2011).

# MACMILLAN'S SERVICE MODEL

Research into the information and support needs of people living with cancer<sup>1</sup> forms the basis for Macmillan's model of accessible support and information.



## 'Guided access' principle

People with cancer and their carers expressed their confusion over the sheer volume of information on cancer in the media, in leaflets and online. They were unsure who to trust and wanted to be guided through the resources available.<sup>2</sup>

As a result, the 'guided access' principle was developed, helping people who use the service to identify their needs and guiding them through a range of options.

## Organisation and display

The organisation and display of information materials should reflect the 'guided access' principle.

Many people diagnosed with cancer have little knowledge of cancer or NHS cancer services. They are unlikely to have previous experience of using a cancer information and support service or anything similar. It's important that the first information they see looks non-threatening. A few general resources, clearly displayed, form a reassuring first introduction to information. For some people, just browsing through general information about cancer or local services provides them with time to think, so they can begin to work out their questions.

Guidance through information materials takes different forms, which are outlined below.

### Finding information

Finding information to answer a service user's question may range from locating a leaflet about a particular type of cancer, to tracing current details for a local support group or a copy of the research article behind a current news story.

The service manager and volunteers need to know their way around the information held so that they can easily find what is needed. Clear headings help staff and volunteers find information, but also help to demystify the information collection process for the user.

### Helping people to find information

Some people will prefer to look for information for themselves. A clear explanation of the subject headings used to classify information and the way it's arranged will help. People will also need to be guided through practical arrangements, such as whether information is available on loan or accessible through the internet or database resources. It's important to assure individuals that help is available if they cannot find the information they want or would like to talk through the issues raised.

**See 'Quality area 8: managing resources – indicator 5' of MQulSS in appendix 1.**

### Providing tools to assess information

Many people want to be able to use electronic resources for themselves. Participants involved in the research<sup>2</sup> by British Market Research Bureau in 2002 expressed concern about how to select reliable information online. Similarly, people receive printed information from a range of sources and may wish to assess it for themselves. Guiding people through information materials therefore includes providing them with tools to assess information.

**See 'Quality area 8: managing resources – indicators 5, 6 and 7' of MQulSS in appendix 1.**

Examples of quality tools to enable people to assess information for themselves include:

- the British Medical Association (BMA) website ([bma.org.uk/patients\\_public/finding\\_reliable\\_healthcare\\_information](http://bma.org.uk/patients_public/finding_reliable_healthcare_information))
- DISCERN ([discern.org.uk](http://discern.org.uk)) see page 70–71 for more information
- *A directory of information materials for people affected by cancer*
- NHS Choices ([nhs.uk/ips](http://nhs.uk/ips)).

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### References

<sup>1</sup> British Market Research Bureau. *Developing information for cancer patients*. 1999. London, BMRB.

<sup>2</sup> British Market Research Bureau. *Review of Macmillan Information and Support Services*. 2002. London, BMRB.

# ORGANISING ACCESSIBLE TIERS OF INFORMATION

People visiting a cancer information and support service for the first time are likely to be nervous, unsure about what the service offers and possibly in distress. The presentation of the information collection therefore has to form part of a supportive overall environment, rather than a daunting bank of knowledge.

The suggested three-tier model for organising information materials is intended to help managers provide 'guided access' to information.

## Three-tier model for cancer information and support services

- 1 Introductory information** General information about cancer and local services, including an introductory guide to the cancer information and support service, could be displayed in a foyer/waiting area or visible immediately on entering the resource area.
- 2 Main display** Information about specific cancers, treatments, living with cancer and support for the family.
- 3 Detailed information** Additional information, including published articles or evidence reviews, available to people who want more information than is available in the main display.

### 1 Introductory information

People entering a cancer information and support service for the first time may feel more comfortable browsing near the entrance before committing themselves to make full use of the service. Where information materials are displayed in a separate room within a centre, strategically placed introductory level information encourages people to use the information room.

Foyers and panels just outside the doorway of a resource room often make good areas for introductory information. Free-standing racks of individual leaflets on the reception desk and around the waiting room can also be used.

Users of introductory information should be alerted to the availability of more detailed information and information in other formats. For example, a sign next to Macmillan's booklet, *The cancer guide*, could state, 'This guide is also available in Braille on request and on CD. Please ask in the information room for details.'

Suggested topics for introductory information include:

- a promotional guide to services offered by cancer information and support service
- local information about support groups, the NHS, local services and access to help and support
- general information about national charities offering support, such as cards for telephone helplines
- general introductory information about cancer.

## 2 Main display

The topics covered in your main display will depend on the issues raised in your needs assessment, and will be defined by your acquisitions policy (**see section 3**).

Information materials in the main display need to be well-presented if people are to find and use them. Consider how many leaflets, books and audiovisual resources you can display well within the space available. Ideally, the racks for leaflets and booklets should enable you to show the full front cover. The subject of a resource is clearest on the front cover, even if the title is repeated on the spine of the publication. What constitutes the front cover may vary in different cultural and language contexts, so check first. Information racks and shelves designed for libraries often take up less floor space than shelves designed for offices. Details of library suppliers are available on the Chartered Institute of Library and Information Professionals website – [buyersguideonline.co.uk](http://buyersguideonline.co.uk)

Signs for the main display need to be very clear. Test out the lettering size with colleagues and volunteers to ensure that the labels for the different topics are obvious and easy to read. Most people find colours and words clearer than letter or number codes.

People will only use information in the more detailed tier if they know that it's available, so it's important to provide notices next to the main display offering additional information.

Suggested topics for main display include:

- risk factors
- screening and diagnosis
- treatments and therapies
- treatment side effects
- using health services
- women's cancers
- men's cancers
- children's cancers
- other common cancers (with a note to indicate that information about rarer cancers is available on request)
- living with cancer
- relationships
- caring
- money matters
- loss and bereavement
- information for children and young people.

### 3 Detailed information

Resources in the detailed information section will be less prominent on entering an information room than the main display. A member of staff or volunteer may select the information for the service user, but it still needs to be clearly organised and available for browsing. The amount of space available will have an impact on the way the information is stored. You could use pigeonholes or magazine boxes. Think carefully before investing in filing cabinets, as they need double the floor space for the storage they provide and information materials can easily slip out of hanging files.

It's important that the detailed subject categories reflect those of the main display. If someone has been looking at information in the main display under 'Men's cancers', they will find the additional information more easily if it's also in a category called 'Men's cancers'.

**See section 4** for more details about classifying information materials. You can also ask for a copy of the *Materials starter kit*, which has been designed to help you choose materials for a new cancer information service. The selection of cancer-specific booklets and leaflets suggested is based on *A directory of information materials for people affected by cancer*. The starter kit is available from the Information and Financial Support team on **020 7840 7829** or by emailing **infomanager@macmillan.org.uk**

# ACCESS FOR PEOPLE WITH DISABILITIES

**Cancer information and support services need to be accessible to people with physical, sensory or learning difficulties. This summary provides a starting point for considering some of the key issues.**

## Where to begin

### **Access services from specialist organisations**

The local NHS Trust may already have arrangements in place for sign language, Braille production and advice.

### **Identify numbers of people**

Information about the approximate numbers of people living with different disabilities locally should be available from local voluntary and statutory organisations. General statistics on the number of people who regard themselves as having a limiting, long-term illness are available in the census information from your local public library.

National statistics on the number of people living with disabilities in the UK are available in the *Family Resources Survey*, which is produced by the Department for Work and Pensions. Visit [research.dwp.gov.uk/asd/frs](https://research.dwp.gov.uk/asd/frs)

### **Consider an accessibility review**

Relevant voluntary organisations and representatives of people who have experience of cancer can be approached to review the accessibility of information materials provided by the service. It's important to get the views and involvement of a range of service users.

### **Access information brokers**

Voluntary organisations, such as the local branch of Action for Hearing Loss (the trading name of the Royal National Institute for Deaf People), can act as 'information brokers', passing on relevant information.

## Needs of people with visual impairment

Around 1 in 30 people in the UK are living with sight loss.<sup>1</sup> Prevalence increases with age and one in five people aged 75 years or older has some degree of sight loss.<sup>1</sup> This is an important factor in providing an accessible service, as older people are the largest age group with a cancer diagnosis.<sup>2</sup>

Very few people with sight loss can see nothing at all; most have some residual vision. They may lose outer vision or central vision.

Providing information in a format that people can read for themselves helps to promote independence.

Each individual will have different needs – for example, large print books are often published in 16 point type but this is not big enough for everyone. There is no single best size, it depends on the user.<sup>3</sup>

For printed documents, other factors come into play, such as contrast and the quality of the paper. It also depends on the kind of media that the person needs to access. For all of these reasons, the Royal National Institute of Blind People (RNIB) recommends a text-based, electronic record of the original as an ideal format to be adapted for each person.<sup>4</sup>

## Needs of people with hearing loss

Hearing loss ranges from people with profound (total) hearing loss to those who are hard of hearing, deafened or become hard of hearing with age.

According to Action on Hearing Loss, about 10 million people in the UK have some form of hearing loss.<sup>5</sup> Most have become deaf or lost some hearing because of old age. They will be able to access information in written English and view video materials with subtitles in line with the general population.

A smaller number of people who were born deaf or lost their hearing early in life rely on British Sign Language (BSL). Estimates suggest that BSL is the first or preferred language of around 70,000 deaf people in the UK.<sup>6</sup> Accessing information in English can be difficult for many BSL users, because it's a visual-gestural language, with its own grammar and principles that are completely different from the grammatical structure of English. One alternative can be supplying a video with both BSL narrative and subtitles. Action on Hearing Loss ([see page 44](#)) has a fact sheet on producing accessible information called *Producing information for people with hearing loss*.

The deaf community is distinct in that it has its own language, culture, history, ways of networking, rules and customs. People who describe themselves as hard of hearing may not consider themselves to be part of the deaf community as English is their first language. They may not have the same problems with written information as people who are profoundly deaf.

## Communication with people who are deaf or affected by hearing loss

### Contact them in advance

- Contact the person first to check if any special arrangements are required.
- Provide written information in advance for them to read if necessary.

### Provide an interpreter

- It's important to use the right kind of interpretation (BSL or Sign Supported English) and to book it in advance (3–4 weeks). Ask the service user which they prefer.
- A fully qualified interpreter is essential for interactions with the healthcare team as a wide range of vocabulary is often needed to cope with medical terminology.

### Think about the setting

- Provide good lighting and a quiet environment.
- Arrange seating so that information staff and the service user can see each other easily to facilitate lip reading if it's being used.
- Allow time, particularly if the individual is lip reading, as it can be extremely tiring.
- Encourage participants to speak one at a time.
- Provide an induction loop for people with a hearing aid.
- Be aware of the length of meetings as interpreters often work in pairs but also need regular breaks.

## Needs of people with learning and literacy difficulties

About 2% of the general population, or 1.2 million people in England, have a learning disability.<sup>7</sup> Some of these individuals may have other disabilities as well, such as sensory or physical impairment. The British Institute of Learning Disabilities ([see page 45](#)) provides information about communication and service provision for people with learning difficulties.

You will also need to consider people with literacy difficulties. Most can read a little, but find it hard to understand and cope with forms, official letters or reports. One in six people in the UK struggle with literacy, reading below the level expected of an 11-year-old.<sup>8</sup> Health writers often assume that readers will have the same understanding of the human body as they do.

## Needs of people with physical disabilities

People with physical difficulties may have problems using standard information materials as well as concerns about physical access to the centre.

Turning pages, particularly if they are shiny and tend to stick together, can be difficult for people with restricted mobility.

With such considerations in mind, look for alternative formats for people with physical disabilities, as well as people with sensory or literacy difficulties.

*The informability manual*<sup>9</sup> is the classic text on making information services more accessible to people with disabilities. It has dated slightly, with the development of new technology, but is a useful point of reference.

## References

- <sup>1</sup> Royal National Institute of Blind People. *Key information and statistics*. <http://www.rnib.org.uk/aboutus/Research/statistics/Pages/statistics.aspx> (accessed 26 October 2011).
- <sup>2</sup> Maddams J, Brewster D, Gavin A, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009;101:541-7
- <sup>3</sup> Royal National Institute of Blind People. *Large print*. [http://www.rnib.org.uk/professionals/accessibleinformation/text/Pages/large\\_print.aspx](http://www.rnib.org.uk/professionals/accessibleinformation/text/Pages/large_print.aspx) (accessed 26 October 2011).
- <sup>4</sup> Royal National Institute of Blind People. *Printed material*. [http://www.rnib.org.uk/professionals/accessibleinformation/printedmaterials/Pages/printed\\_material.aspx](http://www.rnib.org.uk/professionals/accessibleinformation/printedmaterials/Pages/printed_material.aspx) (accessed 26 October 2011).
- <sup>5</sup> Action on Hearing Loss. <http://www.actiononhearingloss.org.uk/your-hearing/about-deafness-and-hearing-loss/statistics.aspx> (accessed 26 October 2011).
- <sup>6</sup> Action on Hearing Loss. *Sign Here: British Sign Language: Where and how to learn it*.
- <sup>7</sup> British Institute of Learning Disabilities. *Factsheet: Learning disabilities*. February 2011. [http://www.bild.org.uk/pdfs/05faqs/Learning\\_Disabilities\\_11.pdf](http://www.bild.org.uk/pdfs/05faqs/Learning_Disabilities_11.pdf) (accessed 26 October 2011).
- <sup>8</sup> National Literacy Trust. *Literacy: State of the nation*. [http://www.literacytrust.org.uk/research/nlt\\_research/2364\\_literacy\\_state\\_of\\_the\\_nation](http://www.literacytrust.org.uk/research/nlt_research/2364_literacy_state_of_the_nation) (accessed 26 October 2011).
- <sup>9</sup> Gregory W. *The informability manual: making information more accessible in the light of the Disability Discrimination Act*. 1996. London, The Stationery Office. ISBN 0-11-702038-9.

# PROVIDING MATERIALS IN DIFFERENT FORMATS

**We all have our own preferences for the format in which we receive information. The following summary is intended to help you think through the formats that you wish to include in your cancer information and support service.**

## Help with providing accessible information materials

Organisations for people with disabilities are often keen to help you make your services accessible. For example, RNIB is campaigning to promote the development of electronic resources that are accessible to people with visual impairment and other disabilities. The British Dyslexia Association has an online style guide to easy-reading materials. Mencap has sourced some materials about cancer for people with learning disabilities and offers a general health website for service users.

Some national charities have local branches. Their members may be prepared to take part in your review of the accessibility of information materials.

### Help with information materials for people with visual problems

**Royal National Institute of Blind People (RNIB)**  
105 Judd Street,  
London WC1H 9NE  
Tel 020 7388 1266  
Fax 020 7388 2034  
Email [helpline@rnib.org.uk](mailto:helpline@rnib.org.uk)  
[www.rnib.org.uk](http://www.rnib.org.uk)

**Action for Blind People**  
14–16 Verney Road,  
London SE16 3DZ  
Tel 020 7635 4800  
[www.actionforblindpeople.org.uk](http://www.actionforblindpeople.org.uk)

### National Talking Newspapers and Magazines

National Recording Centre,  
Heathfield, East Sussex TN21 8DB  
Tel 01435 866102  
Fax 01435 865422  
Email [info@tnauk.org.uk](mailto:info@tnauk.org.uk)  
[www.tnauk.org.uk](http://www.tnauk.org.uk)

### Help with information materials for people with hearing loss

**Action on Hearing Loss**  
19–23 Featherstone Street,  
London EC1Y 8SL  
Tel 020 7296 8000  
Textphone 020 7296 8001  
Email [informationline@hearingloss.org.uk](mailto:informationline@hearingloss.org.uk)  
[www.actiononhearingloss.org.uk](http://www.actiononhearingloss.org.uk)  
Contact details for Northern Ireland, Scotland and Wales are on the main website.

### **British Deaf Association**

18 Leather Lane,  
London EC1N 7SU  
**Tel** 020 7405 0090  
**Email** [bda@bda.org.uk](mailto:bda@bda.org.uk)  
[www.bda.org.uk](http://www.bda.org.uk)  
Contact details for regional offices  
are available on the website.

### **Sense**

101 Pentonville Road,  
London N1 9LG  
**Tel** 0845 127 0060  
or 020 7520 0999  
**Textphone** 0845 127 0062  
or 020 7520 0959  
**Fax** 0845 127 0061  
or 020 7520 0958  
**Email** [info@sense.org.uk](mailto:info@sense.org.uk)  
[www.sense.org.uk](http://www.sense.org.uk)

### **Guidance on easy-to-read information materials**

#### **British Dyslexia Association**

Unit 8 Bracknell Beeches,  
Old Bracknell Lane,  
Bracknell RG12 7BW  
**Tel** 0845 251 9003  
**Fax** 0845 251 9005  
**Email** [admin@bdadyslexia.org.uk](mailto:admin@bdadyslexia.org.uk)  
[www.bdadyslexia.org.uk](http://www.bdadyslexia.org.uk)

#### **British Institute of Learning Disabilities**

Campion House,  
Green Street, Kidderminster,  
Worcestershire DY10 1JL  
**Tel** 01562 723010  
**Fax** 01562 723029  
**Email** [enquiries@bild.org.uk](mailto:enquiries@bild.org.uk)  
[www.bild.org.uk](http://www.bild.org.uk)

#### **National Institute of Adult and Continuing Education (NIACE)**

Chetwynd House,  
21 De Montfort Street,  
Leicester LE1 7GE  
**Tel** 0116 204 4200/4201  
**Fax** 0116 285 4514  
**Email** [enquiries@niace.org.uk](mailto:enquiries@niace.org.uk)  
[www.niace.org.uk](http://www.niace.org.uk)

#### **Mencap**

123 Golden Lane,  
London EC1Y 0RT  
**Tel** 020 7454 0454  
**Fax** 020 7608 3254  
**Email** [information@mencap.org.uk](mailto:information@mencap.org.uk)  
[www.mencap.org.uk](http://www.mencap.org.uk)  
Contact details for Northern Ireland  
and Wales are on the website.

#### **Plain English Campaign**

PO Box 3, New Mills,  
High Peak SK22 4QP  
**Tel** 01663 744409  
**Fax** 01663 747038  
**Email** [info@plainenglish.co.uk](mailto:info@plainenglish.co.uk)  
[www.plainenglish.co.uk](http://www.plainenglish.co.uk)

#### **The Word Centre**

27 Norfolk Hill,  
Sheffield S35 8QA  
**Tel** 0114 257 1400  
**Fax** 0114 257 1528  
**Email** [df@wordcentre.co.uk](mailto:df@wordcentre.co.uk)  
[www.wordcentre.co.uk](http://www.wordcentre.co.uk)

## Use of formats for people with different disabilities

Format	Visual impairment	Hearing loss	Literacy/ learning difficulties	Physical disability
<b>Standard print</b>	<p>Clearly presented text can be read using electronic text readers, provided it's not in columns.</p> <p>Paper should be thick enough not to read through from the other side.</p> <p>Black text on pale yellow matte paper is best.</p>	<p>Printed materials are acceptable for most people.</p>	<p>Text should be well-spaced. Columns can be confusing.</p> <p>New headings or sections at the top of each page make text easier to follow.</p> <p>Pictures may be taken literally, so need to be absolutely right.</p>	<p>Clear print on matte paper should be used to avoid reflections and paper sticking together.</p>
<b>Large print</b>	<p>Text of at least 16 point with clear spacing.</p> <p>Increasing the font on a computer or photocopier can help improve access.<sup>1</sup></p> <p>Macmillan can provide large print versions of our materials on request.</p>	<p>Text of 16 point is usually sufficient.</p>	<p>Text of 16 point is usually sufficient as long as it is well-spaced and clear.</p>	<p>Text of at least 16 point for some disabilities where there is also visual impairment.</p>
<b>Audio (CD and MP3 files)</b>	<p>Assistance may be required to navigate the recording.</p> <p>Macmillan produces some of its information in audio format.</p>	<p>Not usually appropriate.</p>	<p>Useful format as long as the information is clear.</p> <p>Visual guides are sometimes needed alongside audio resources.</p>	<p>Audio versions of text may help by avoiding the need to turn pages and by reducing fatigue.</p>
<b>Digital</b>	<p>Web, software and CD-Rom resources are widely used with an electronic text reader, provided text is not in columns.</p>	<p>Online and digital resources are widely used.</p>	<p>Widely used information source.</p>	<p>Internet used as information source and for communication. An increasing number of support groups are web-based.</p>

<b>Format</b>	<b>Visual impairment</b>	<b>Hearing loss</b>	<b>Literacy/ learning difficulties</b>	<b>Physical disability</b>
<b>Radio/ television</b>	Radio is an important resource but many people with a visual impairment still watch TV.  Some TV programmes have audio description.	Teletext is a useful source of information as well as providing subtitles.  Some TV programmes include signing.	Widely used information source.	Radio and television both used as information sources.
<b>DVD, video downloads</b>	Users can listen to resources even if they cannot see them clearly.  Text descriptions are sometimes available for action on DVD.	There are few signed DVDs or video downloads available.  Subtitles can be selected on DVDs.	Widely used information source.	Widely used information source.
<b>Helpline</b>	Telephone and email services.	Telephone, email, textphone and text relay services.	Telephone and email services.	Telephone and email services.
<b>Braille</b>	Few people read Braille fluently but it's crucial for those who do.  Macmillan can produce Braille versions of its materials on request.	Not usually applicable.	Not usually applicable.	Not usually applicable.
<b>Moon</b>	Moon is a simple, tactile alphabet. It's easier to learn than Braille, but few people use it.	Not usually applicable.	Not usually applicable.	Not usually applicable.

### Reference

<sup>1</sup> Under the Copyright (Visually Impaired Persons) Act 2002, one photocopy enlargement of a document may be made for someone with a visual impairment if no published large print version exists.



# ACCESS FOR PEOPLE WITH DIVERSE CULTURES

**Cancer information and support services need to be appropriate to the beliefs, attitudes and values of the diverse cultural communities within their localities.**

**See 'Quality area 4: user-centred service – indicator 3' of *MQuISS* in appendix 1.**

People who have moved to the UK may have issues with accessing services. It's important to note that these may be different from the issues for their children and grandchildren. Different members of the same family may prefer different languages and formats. Supplying information materials in appropriate languages is only part of the process; the whole service should be sensitive to the needs of the various communities in the local area.

## Working with local communities

The best way to develop information services to meet the needs of local communities is to work with them. It's important to establish a trusting relationship with local groups before starting to work on formal assessments of needs, as you could be asking the wrong questions of the wrong people. Think of the approach as learning from each other, rather than a 'needs assessment'.

## Using interpretation services

Most NHS Trusts have interpretation services and networks of bilingual health workers. It's important to ask people about their preferred language and book an interpreter in advance. Although some Trusts expect bilingual health workers to be available to translate at short notice, most have not been trained to act as interpreters. Health workers from within the Trust are also likely to have limited time for the consultation. An experienced health interpreter will have the medical vocabulary to support the interaction and will have allocated time for the session.

The use of family members as interpreters is a delicate issue. They should not be put in the position of having to become interpreters by default. It's not advisable to use family members as interpreters in clinical situations due to considerations of quality and patient confidentiality. However, they may be appropriate in a general discussion about menu choices or a patient's comfort. It's also important to find out the preference of the individual.

## Identifying resources in diverse languages

Many of the resources about cancer available in languages other than English are about screening for cancer. The reason for this is historical, as the NHS Cancer Screening Programme was the first body to translate its materials into a range of languages.

Many resources have been developed for local rather than national use. These tend to include general guides to local services offered. It's worth checking with your cancer network and local information service providers, such as your Patient Advice and Liaison Service (PALS) in England and social services, whether there are resources you could use.

### Support and resources from Macmillan

Macmillan produces a small amount of translated information, which can be found at [macmillan.org.uk/cancerinformation/aboutcancer/foreign.aspx](https://macmillan.org.uk/cancerinformation/aboutcancer/foreign.aspx)

Our cancer support specialists, on **0808 808 00 00**, can arrange for three-way, interpreted conversations to take place when a caller needs this service.

Macmillan welcomes requests to translate its information resources into other languages, although this may not always be possible or appropriate. For more information, email [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)

Macmillan also produces *A directory of information materials for people affected by cancer*, which lists selected booklets and leaflets for people affected by cancer, along with brief summaries and readability scores. You can order a free copy at [be.macmillan.org.uk](https://be.macmillan.org.uk) or by calling **0808 808 00 00**. You can also access the directory online at [macmillan.org.uk/cancerpublications](https://macmillan.org.uk/cancerpublications)

Macmillan's *Guide to BME cancer resources* lists resources that are suitable for black and minority ethnic users. This guide and sample pages from the directory can be downloaded at [macmillan.org.uk/cancerpublications](https://macmillan.org.uk/cancerpublications)

## Developing information materials in diverse languages

There is sometimes a temptation to assume that by translating a leaflet into diverse languages it will increase the accessibility of the service. Direct translation of resources is often inappropriate, as information needs to be presented in the appropriate context within different cultures, including minority ethnic cultures where the first language is English, for example, some African-Caribbean communities. Some languages are also used in the spoken rather than the written form, making audio resources more appropriate.

Providing information in an appropriate format is only the first step to accessibility. People may also need advocacy-type support to understand the information and to help them make informed decisions.

### Sources of help and information

#### Institute of Translation & Interpreting

Fortuna House, South Fifth Street, Milton Keynes MK9 2PQ

Tel 01908 325250

Fax 01908 325259

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

[www.iti.org.uk](http://www.iti.org.uk)

An independent UK professional association of translators and interpreters; has an online directory.

#### Language Line

25<sup>th</sup> Floor, 40 Bank Street, Canary Wharf, London E14 5NR

Tel 0800 169 2879

[www.language.co.uk](http://www.language.co.uk)

Company providing translation services to the public sector and NHS.

**For signposting to sources of advice, contact the Information and Financial Support team on 020 7840 7829 or email [infomanager@macmillan.org.uk](mailto:infomanager@macmillan.org.uk)**



Financial Planning 45 07

**MANAGING MONEY DAY-TO-DAY**

**WE ARE MACMILLAN CANCER SUPPORT**

**It all adds up series**  
A guide to budgeting and staying on top of your everyday finances 2011-12

# CHECKLIST AND FURTHER READING

## Checklist

Check physical access to service (involving individuals and local support groups)

Develop services on 'guided access' model

Involve local support groups for people with disabilities and representatives of local community groups in selection of information

Select information materials in accessible formats

Check availability and develop processes for sign language interpretation

Select information materials in appropriate languages

Check availability and develop processes for language interpreters

Organise information materials with clear, accessible headings

Ensure relevant information is available for people of different age groups, disabilities, ethnic background, gender, religion or belief, rarer cancers, sexual orientation and socioeconomic background

If material is designed to be viewed online, ensure colours in the background and foreground contrast enough to meet accessibility standards

For online materials, give the option to read the text in larger font sizes

Review processes to ensure accessibility

## Further reading

El Ansari W, Newbigging K, Roth C, et al. The role of advocacy and interpretation services in the delivery of quality healthcare to diverse minority communities in London, United Kingdom. *Health & Social Care in the Community*. 2009; 17(6):636–646.

Equality and Human Rights Commission. *Your responsibilities when delivering services*. <http://www.equalityhumanrights.com/advice-and-guidance/guidance-for-service-providers/your-responsibilities-when-delivering-services/> (accessed January 2011).

Jacobs-Lawson JM, Schumacher MM, Hughes T, Arnold S. The relationship between lung cancer patients' educational level and evaluation of their treatment information needs. *Journal of Cancer Education*. 2009; 24(4):346–50.

O'Regan P, Drummond E. Cancer information needs of people with intellectual disability: A review of the literature. *European Journal of Oncology Nursing*. 2008; 12:142–147.

Posma ER, van Weert JC, Jansen J, Bensing JM. Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*. 2009; 8:1.

Royal National Institute for the Blind. *Accessible information*. [Guidance on most major formats]. [http://www.rnib.org.uk/professionals/accessibleinformation/Pages/accessible\\_information.aspx](http://www.rnib.org.uk/professionals/accessibleinformation/Pages/accessible_information.aspx) (accessed January 2011).

Royal National Institute for the Blind. *See it right. Practical advice on designing, producing, and planning for accessible information* (including printed, audio, tactile and electronic). Book and CD. Order via website: [http://www.rnib.org.uk/professionals/accessibleinformation/Pages/see\\_it\\_right.aspx](http://www.rnib.org.uk/professionals/accessibleinformation/Pages/see_it_right.aspx) or phone 0303 123 9999.

Royal National Institute for Deaf People. *Is your service accessible?* [http://www.rnid.org.uk/information\\_resources/information\\_for\\_health\\_professionals/is\\_your\\_service\\_accessible/](http://www.rnid.org.uk/information_resources/information_for_health_professionals/is_your_service_accessible/) (accessed January 2011).

Smith SK, Trevena L, Nutbeam D, Barratt A, McCaffery KJ. Information needs and preferences of low and high literacy consumers for decisions about colorectal cancer screening: utilizing a linguistic model. *Health Expectations*. June 2008. 11(2):123–36.

Thompson R, Van Der Molen B. Access to cancer services – do culture and ethnicity make a difference? *European Journal of Cancer Care*. 2009; 18(1): 3.

Waller J, Robb K, Stubbings S, et al. Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England. *British Journal of Cancer*. 2009; 101: S24–S30.

Zebrack B. Information and service needs for young adult cancer patients. *Supportive Care in Cancer*. 2008; 16(12):1353–60.



AN,  
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CANCER SUPPORT

Coping with fatigue

Contents





# CHOOSING INFORMATION MATERIALS

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Cancer Support provides practical information and financial support for better cancer care.

of us will get cancer. us are living with it. cted by cancer. We are Mac...

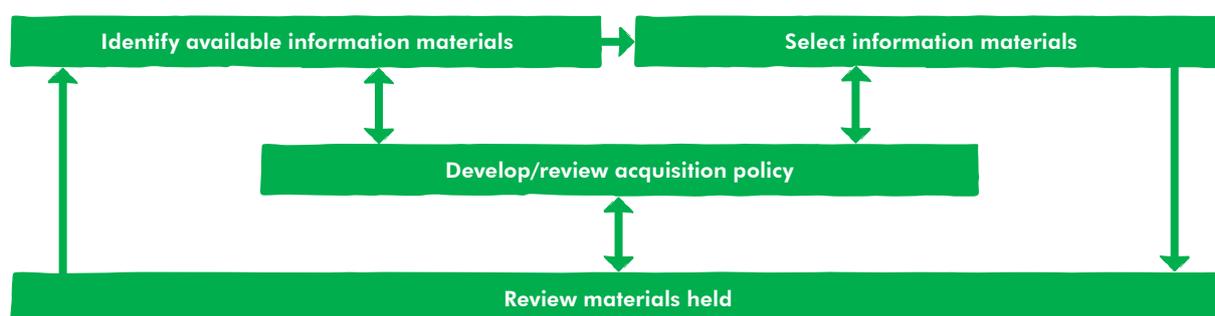
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# STARTING POINTS

'People do not buy food that is past its sell by date, so why should they accept information that is not current? It is just as dangerous – if not more so.'<sup>1</sup>

Mark Duman, *Producing patient information: how to research, develop and produce effective information resources*

## Choosing information materials



Having identified the topics and formats for information materials needed by people who use your service, you can start to select information materials to meet these needs. The budget, display areas and storage facilities may limit what is possible. All information service managers need to prioritise topics, identify how many titles they can hold and order stock accordingly.

An acquisitions policy is the key to successfully choosing information. It should outline the topics of information to be held and the inclusion criteria you will use for consistent selection of the best available materials.

Macmillan's *Materials starter kit* has a list of suggested inclusion criteria for an acquisitions policy and initial materials to order for a cancer information and support service. For a copy of the starter kit, contact the Information and Financial Support team on **020 7840 7829** or email **infomanager@macmillan.org.uk**

A *directory of information materials for people affected by cancer* provides a wider resource to help you consider materials to match the local information needs you have identified, and can be ordered at **be.macmillan.org.uk**

### Reference

<sup>1</sup> Duman M. *Producing patient information: how to research, develop and produce effective information resources*. 2003. London, The King's Fund.

# DEVELOPING AN ACQUISITIONS POLICY

**All cancer information and support services need a written policy on which to base selection of information materials. This is called an acquisitions policy. The acquisitions policy should be developed with an advisory group and include the range of topics and formats to be covered (the scope of the collection) and inclusion criteria for selecting materials.**

## Establishing an advisory group

Setting up an advisory group provides a forum to discuss the needs of potential service users and develop an acquisitions policy to meet these needs. Service users or potential users from local cancer support groups should be invited to join the group. In addition to the staff, volunteers and users of the cancer information and support service, the involvement of a local librarian can be extremely helpful.

The advisory group can also provide practical help, as it's impossible for one person to read all the information that a cancer information and support service could potentially contain. Clear selection criteria enable members of the advisory group to assist with the assessment of materials for inclusion in the information stock.

Members of the advisory group can write summaries of information materials, which readers can use to assess the relevance of a particular resource to their needs.

## Determining the scope of the collection

On the basis of the information needs you have identified, the advisory group will establish the scope of the information materials to be included, in terms of both the subject matter and the format. The agreed scope should then be described in the written acquisitions policy.

Research conducted by the British Market Research Bureau<sup>1</sup> identifies topics that users of cancer information services expect to see covered. These are diet, financial help, cancer treatment and its side effects, and details about support groups. The report also indicates that information materials should address the needs of people living with cancer and carers. This general research data combined with the results of your local needs assessment will provide you with a good basis on which to determine the scope of your collection.

## Considering the balance of medical and support information in designing the collection

**Medical information** Prevention/health promotion, risk, genetics and screening, specific types of cancer, treatment and side effects.

**Support information** Benefits, social services, self-help and support groups, employment, legal rights, insurance, holiday and convalescence, transport, residential care and respite care.

**Complementary therapies** Acupuncture, aromatherapy, herbal remedies, colour therapy, crystal therapy, visualisation, healing, reflexology, relaxation techniques, spiritual care, yoga, art therapy, hypnotherapy, music therapy and homeopathy.

**Diet** Information about nutrition for people with cancer and general healthy eating for people trying to reduce their risk of cancer.

**Psychological** Counselling and family therapy.

**Practical day-to-day living** Obtaining special equipment to help around the home, employment and education.

**Organisations and groups** Hospice and palliative care services, national and local cancer organisations and groups and community support organisations, for example, Age UK.

## Establishing the inclusion criteria for your acquisitions policy

The key to an acquisitions policy is the inclusion criteria used for selecting or rejecting cancer information materials.

These criteria need to be agreed by the advisory group and be available to service users. Keeping to the criteria helps to define the boundaries of information materials that are held by the service and assists budget management.

To meet inclusion criteria for *A directory of information materials for people affected by cancer*, resources must:

- cover cancer management or living with cancer
- be intended for people affected by cancer
- have been produced in the UK in the last five years
- be no more than two years old if they are primarily about benefits and grants
- be intended for national distribution
- be clearly marked with a date of publication (eg 2009 or March 2010)
- be available in print at the time of going to press.

DISCERN appraisal is carried out on information materials containing details about treatment. Most services opt to use only materials with a score of 3, 4 or 5, and state this in their acquisitions criteria. For further information about DISCERN, **see pages 70–71.**

Applying the same criteria as those used for *A directory of information materials for people affected by cancer* for the assessment of materials can save time.

Inclusion criteria are usually stated as a series of descriptive statements, such as:

- All materials will be relevant to the cancer-related information needs of the local community (specify topics from findings).
- Materials are provided in [specified] languages and [specified] formats to meet local needs.
- Information on treatment will only be held if it achieves a DISCERN score of 3+.
- All materials will be published in the UK for a country-wide audience or for [named region].
- Only dated materials will be included.
- Information materials produced more than five years ago won't held unless there is a specified (and recorded) reason for doing so.

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### Reference

<sup>1</sup> British Market Research Bureau. *Review of Macmillan cancer information and support services*. London: BMRB, 2003.

# FINDING RELEVANT MATERIALS

**Before you begin to choose information that matches your acquisitions policy, you will need to find out what information is available.**

## Finding national cancer-related information

*A directory of information materials for people affected by cancer was developed as an aid to people running cancer information and support services. The directory covers information about cancer, cancer treatments and living with cancer. To order a copy, visit [be.macmillan.org.uk](http://be.macmillan.org.uk)*

Databases are available to help you identify research papers about cancer. They are available online and through subscription services (fee-paying databases available on CD-Rom or online). These can help build up reference information in the third tier of your information collection (detailed information) and to help you find the answers to complex queries from people who use your service. Tips on database/online search techniques are included in the next section. A good place to start is the NHS Evidence website – [evidence.nhs.uk](http://evidence.nhs.uk)

Research papers are sometimes only available in summary form online. If you need the full text of an article, you can obtain a single photocopy on inter-library loan. A postgraduate medical library or public library will be able to arrange inter-library loans. If you are likely to need these on a regular basis and are charged more than £8 per item, it may be worth setting up your own inter-library loan account. For more information, visit [bl.uk/reshelp/atyourdesk/docsupply](http://bl.uk/reshelp/atyourdesk/docsupply)

## Finding local information

Members of the local multidisciplinary cancer team should be able to advise you of any information materials produced locally and tell you if there is a formalised information strategy for your cancer network. They may not, however, be aware of information produced about your hospital or NHS locality. It's worth looking through resources held by local Patient Advice and Liaison Service (PALS) or health information services, asking them about the suppliers and referrals between services.

Local cancer self-help and support groups are likely to produce posters or cards to promote their group meetings.

Most of the local information relevant to people affected by cancer will relate to their support needs and not necessarily be cancer-specific. Visiting your local Citizens Advice and public library will help you to identify local services and organisations that produce relevant information.

You can search for details of local cancer self-help and support groups on the Macmillan website [macmillan.org.uk/supportgroups](http://macmillan.org.uk/supportgroups)

## Finding non-cancer specific information

Identifying good non-cancer information relevant to the needs of your users can be time consuming. It's worth checking your local library and Citizens Advice to see what is available.

The following websites have useful information and advice. Check their publications and information pages for leaflets and factsheets – many will be free of charge or available to download.

### General health promotion

**Health and Social Care in Northern Ireland**  
[www.n-i.nhs.uk](http://www.n-i.nhs.uk)

**NHS Choices (England)**  
[www.nhs.uk](http://www.nhs.uk)

**NHS Health Scotland**  
[www.healthscotland.com](http://www.healthscotland.com)

**Patient UK**  
[www.patient.co.uk](http://www.patient.co.uk)

**Scotland's Health on The Web**  
[www.show.scot.nhs.uk](http://www.show.scot.nhs.uk)

**Welsh Government**  
[www.wales.gov.uk](http://www.wales.gov.uk)

### Health and children/young people

**Directgov**  
[www.direct.gov.uk/youngpeople](http://www.direct.gov.uk/youngpeople)  
Information and support for young people

**The Site**  
[www.thesite.org](http://www.thesite.org)  
Young person's gateway to information and advice on health and a range of other issues, run by the charity YouthNet UK.

### Youth Access

[www.youthaccess.org.uk](http://www.youthaccess.org.uk)  
Searchable directory of hundreds of agencies providing information, advice, counselling and support.

### Using health services

**Health and Social Care in Northern Ireland**  
[www.n-i.nhs.uk](http://www.n-i.nhs.uk)

**NHS Direct England**  
[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

**NHS24 (Scotland)**  
[www.nhs24.com](http://www.nhs24.com)

**NHS Direct Wales**  
[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

### Financial issues

**Citizens Advice**  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)  
To search for your nearest CAB or visit the online CAB advice guide is at [adviceguide.org.uk](http://adviceguide.org.uk)

**Directgov**  
[www.direct.gov.uk](http://www.direct.gov.uk)  
Government information portal with facts on benefits, family finances and managing debt. If you live in Northern Ireland, visit [nidirect.gov.uk](http://nidirect.gov.uk)

## Welfare Rights Service

Check your council website for details of local offices.

## Caring

### Carers UK

[www.carersuk.org](http://www.carersuk.org)

### Crossroads Care

[www.crossroads.org.uk](http://www.crossroads.org.uk)

### Directgov

[www.direct.gov.uk/en/caringforsomeone](http://www.direct.gov.uk/en/caringforsomeone)

### Princess Royal Trust for Carers

[www.carers.org](http://www.carers.org)

## Complementary therapies

### British Complementary Medicine Association

[www.bcma.co.uk](http://www.bcma.co.uk)

### Institute for Complementary and Natural Medicine

[www.i-c-m.org.uk](http://www.i-c-m.org.uk)

### National Center for Complementary and Alternative Medicine

<http://nccam.nih.gov>

US government website with comprehensive and objective information.

## Loss and bereavement

### Bereavement Advice Centre

[www.bereavementadvice.org](http://www.bereavementadvice.org)

### Cruse Bereavement Care

[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

### The Compassionate Friends

(bereaved parents and families)

[www.tcf.org.uk](http://www.tcf.org.uk)

### Winston's Wish

(bereaved children and young people)

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

## Relationships

### Institute of Family Therapy

[www.instituteoffamilytherapy.org.uk](http://www.instituteoffamilytherapy.org.uk)

### Relate

[www.relate.org.uk](http://www.relate.org.uk)

## Dictionaries and reference materials

Reference books and CD-Roms, particularly medical reference works, are an important resource to help you to answer complex queries. The Chartered Institute of Library and Information Professionals buyers' guide website – [buyersguideonline.co.uk](http://buyersguideonline.co.uk) – has details of how to obtain publishers' catalogues (books, audiovisual, and electronic resources).

# ELECTRONIC SEARCHING TECHNIQUES

Whether you are using the internet, a local library database or a database on subscription (such as a CD-Rom), similar principles apply for searching. If the search terms you use are too broad, you will find irrelevant references. If the search terms are too narrow (specific), you risk not finding any records at all.

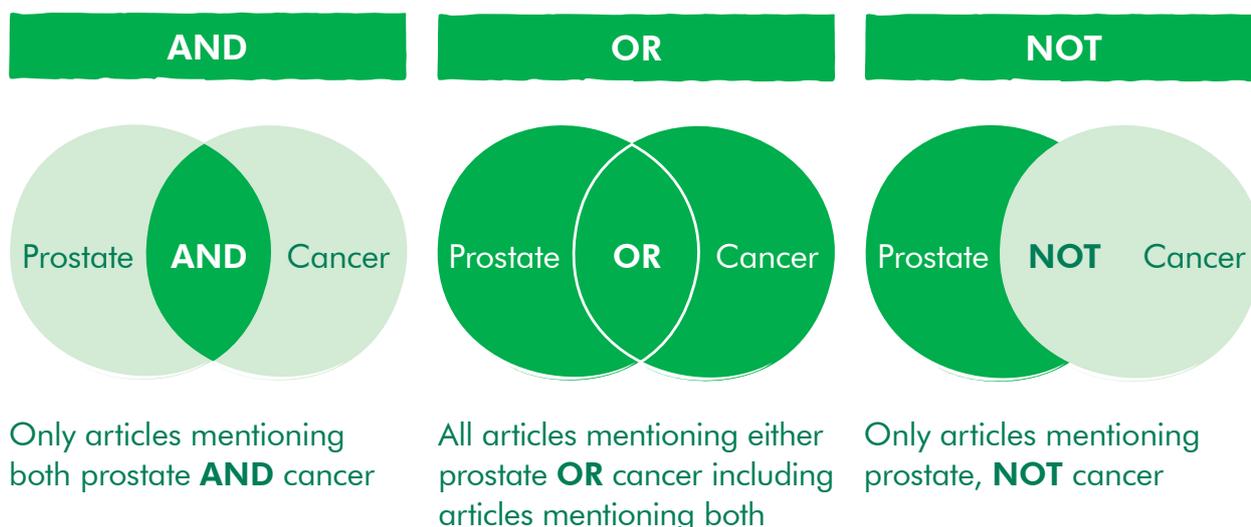
See 'Quality area 8: managing resources – indicator 6' of *MQuISS* in appendix 1.

## Combining terms

Most databases operate by allowing you to combine search terms in different ways. The most common combinations are AND, OR and NOT. These combine terms using the algebraic formulae known as Boolean logic.

Typing more than one word will automatically perform an AND search. This will only return search results that contain **all** of the words you entered. If you use OR, you will broaden your search to retrieve all entries that include any of the terms you searched for.

### Boolean logic for searching databases



It's worth checking any guidance on 'advanced searching techniques' within the database you are using. Some databases use symbols rather than words to combine terms. Additional operators to combine terms are also included in some systems, such as NEAR for terms within the same paragraph. For example, community NEAR care will retrieve 'care in the community' as well as 'community care'.

## Truncation

If fewer articles emerge from a search than you were expecting, you can use truncation to broaden your search. Entering 'cancer' by itself will not retrieve 'cancers' or 'cancerous'. Most databases will have a truncation option to take the first part of a word and search for all the words that start with that 'stem' by adding a symbol known as a wildcard. The symbol will vary by database. Google uses the \* symbol.

## Examples of truncation and searching with a wildcard

Nutri\* search results may include:

- nutrient
- nutritious
- nutritional.

Health\* search results may include:

- health
- healthy
- healthier.

## Field-specific searching

Searching for terms within a specific field (or data entry category) will help to reduce the number of inappropriate items retrieved. If you want to find articles focusing on a particular type of cancer, you could restrict your search by searching only for words in the title field.

You can also use the field-specific search function to narrow the search down to only search the titles of articles or only the body text.

## Phrase searching

If you know the precise title or a phrase within a text, most databases will allow you to search for exact phrases. On most online search engines you can use speech marks to create a phrase, for example "information prescriptions". Search engines also have advanced search options that allow you to search for a phrase, all the words or a single word.

## Searching issues

Although the same basic principles apply to searching online as to other databases, the unregulated nature of the internet means that there are other issues to consider. To be sure that a website is genuine, contact the organisation for their website address or check their publicity materials to see if they publish a website address.

Website addresses also known as domain names, such as **macmillan.org.uk** give an indication of the type of organisation and country of origin. However, as anyone can register a domain name, the website address is not a guarantee of its legitimacy. You can use a WHOIS look-up (eg **http://whois.domaintools.com**) to check who registered a domain name.

Web addresses may include: **.org** (associations and organisations); **.com** (commercial); **.nhs** (NHS); **.ac** (university); **.gov** (government); **.info** (information source). International and US addresses have no country code, but UK registered domain names end with **.uk**.

Most internet searches are either carried out on search engines ('web crawlers') or on 'directory' sites. Search engines are websites developed to let you search across the internet. Most are free to use, funded by advertising revenue. Search engines operate in different ways and link to a different range of sites, so it's worth running the same search on different search engines. Looking at the 'About us' or equivalent section will give you some indication of how the search engine operates and the editorial policies for the site. Many search engines combine features and some, called meta search engines, search across the results from several individual search engines.

### Online search tools – principal types

#### Search engines (web crawlers)

Search engines trawl through the coding behind a website. The most popular search engine is Google. Search engines produce both organic search results (determined by complex 'algorithms' that they use to calculate the most relevant results) and paid search results, which companies or organisations bid to be ranked amongst. Paid search results are clearly marked under headings such as 'Ads' or 'Sponsored listings'.

Examples include Google ([google.co.uk](http://google.co.uk)); Yahoo ([uk.yahoo.com](http://uk.yahoo.com)); and Bing ([bing.co.uk](http://bing.co.uk)).

#### Directory sites

These sites arrange links into categories and subcategories. Most are maintained by human editors rather than web crawlers. Some popular search engines also have their own web directories. Once you have searched in a directory, it will propose alternative or related terms to assist with your search. Directories may be slower than web crawler sites to include new sites. Examples include the Open Directory Project – [dmoz.org](http://dmoz.org)

#### Meta search engines

Sites that search across the results of several search engines.

Examples include Dogpile – [dogpile.com](http://dogpile.com)

#### Health gateways

Sites applying stated quality criteria to linked sites. Most will just link to recognised sites, rather than letting the user search across all linked sites from one point. Examples include MedlinePlus ([nlm.nih.gov/medlineplus](http://nlm.nih.gov/medlineplus)) and NHS Evidence ([evidence.nhs.uk](http://evidence.nhs.uk)).

#### Search engine index

Provides an index of the search engines available for more than 200 countries.

Examples include [search-engine-index.co.uk](http://search-engine-index.co.uk)

# ASSESSING THE QUALITY OF INFORMATION MATERIALS

Once you have identified information materials you could use, you can begin the process of selecting materials to use in your service. The key aspects to consider when assessing the quality of information materials are content, presentation and accessibility.

## Content

The content needs to be presented correctly for the intended audience, based on up-to-date evidence. Involving people affected by cancer throughout the production process is also considered good practice. It's particularly important for information about treatments to refer to risks (harms) and benefits of treatment; side effects; and the implications of choosing not to be treated. The claimed risks and benefits should be referenced, so that sources can be verified if necessary.

## Assessing content

**Audience** Would people who use your service match the intended audience?  
Have users been involved in the production or review of the resource?

**Communication** Is the topic clearly introduced, with clear and concise explanations from a lay person's perspective?

**Clarity** Have medical terms been explained or replaced with appropriate lay terms?

**Currency/date** Is the information dated and sufficiently current for your needs?

**Evidence base** Are claims, particularly in relation to treatment risks or benefits, referenced sufficiently clearly for you to be able to trace the original sources?

### Presentation

The presentation of information has a profound impact on how easy it is to read or to use. If information materials have been badly designed, the flow of the content may not be clear, making the resource difficult to read or understand. A poor design can mean that information materials look irrelevant or boring, so may not be selected.

#### Assessing presentation

**Format** Is the format (print, audiovisual, language) suited to the content of the resource?

**Layout** Is the layout clear? Can you follow the sequence of the content?

**Text style** Is it a non-serif font (such as Helvetica, Arial or Tahoma) of 12 point or over?

**Illustrations** Are the illustrations relevant to the content and/or welcoming for the people who use your service?

**Cover** Is the content and audience clear from the cover? A clear cover eases display and reduces inappropriate self-selection.

### Accessibility

Ensuring the accessibility of information is covered in more detail in Section 2 of this guide. In terms of selecting information materials, the quality criteria you apply will be determined by the format, language and level of complexity needed by people who use your service.

Under the Copyright (Visually Impaired Persons) Act 2002, one enlarged photocopy may be made for someone with a visual impairment if no published large print version exists. Contact the publishers if you feel that you would make frequent use of a publication in large print, on tape, in Braille or in another language – they may not be aware of the demand.

There is no single tool to assess the accessibility of information materials for all groups of users, as they will have different needs. The best way to assess the accessibility of information materials for people who use your service is to ask them to look at materials and tell you what they have understood of the content as presented.

## Assessing accessibility

**Format** Is the format (print, audio-visual, language, text size) suited to the needs of your users?

**Communication** Has the text been written in short, simple sentences?

**Paper** Is the paper thick enough to prevent text showing through from the opposite side? Is it a pale, matte paper, to minimise access problems for people with visual problems?

**Text style** Is it a non-serif font (such as Helvetica, Arial or Tahoma) of 12 point or over? If the font is smaller than 12 point, is a large print version available?

**Illustrations** Are text descriptions of illustrations given on audio and electronic versions of resources? Are the illustrations culturally appropriate for users of your service?

**User involvement** Is there evidence of user involvement in the development of the resource to ensure that it meets the needs of the target group?

## The Information Standard

The Information Standard is a quality assurance scheme for producers of health and social care information in England. Launched in 2009, it aims to help people identify information that comes from a trustworthy source.

To become a member of the scheme, organisations must show that they have strictly-managed processes in place to produce information that is:

- accurate
- impartial
- balanced
- evidence-based
- accessible
- well-written.

Any information producer that is a member of the Information Standard will display the Standard logo on their print and online information materials, as a mark of quality. For more information, visit [theinformationstandard.org](http://theinformationstandard.org)



# CONSUMER HEALTH INFORMATION QUALITY TOOLS

Applying consumer health information quality tools can be time-consuming, but helps to ensure the standards for information used. This section provides information about some of the tools available to help with this assessment.

See 'Quality area 8: managing resources – indicators 5 and 6' of **MQUISS** in appendix 1.

## DISCERN

The DISCERN project, funded from 1996 to 1997 by The British Library and the NHS Executive Research Development Programme, resulted in the first standardised index of quality in consumer health information.<sup>1</sup> It was developed in recognition of the need for a general set of quality criteria for written health information on treatment choices.

DISCERN cannot be used to assess the scientific quality or accuracy of the evidence on which the publication is based (as this would require checking against other sources) or to assess the effectiveness or accessibility of its presentation.

### Interpreting DISCERN scoring

 *****	<p><b>Appraised and of good quality with very few shortcomings</b></p> <p>The publication rated high (four or above) on the majority of questions. A high overall quality rating indicates that the publication is 'good' quality; it is a useful and appropriate source of information about treatment choices.</p>
 ****	<p><b>Appraised and of good quality with some shortcomings</b></p> <p>The publication rated fair to high (three or above) on the majority of questions. A high overall quality rating indicates that the publication is 'good' quality with only a few shortcomings; it is a useful and appropriate source of information about treatment choices.</p>
 ***	<p><b>Appraised and of fair quality with some shortcomings</b></p> <p>The publication rated high and low on a similar number of questions, or the majority of questions rated in the mid-ranges (three). A moderate overall quality rating indicates that the publication is 'fair' quality – it is a useful source of information about treatment choices but has some limitations. Additional information or support would definitely be needed.</p>

 <b>**</b>	<p><b>Appraised and of low quality with major shortcomings</b>                  The publication rated low to fair (three or below) on the majority of questions. A low overall quality rating indicates that the publication is of low quality; it has major shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and should not be used.</p>
 <b>*</b>	<p><b>Appraised and of poor quality with very serious shortcomings</b>                  The publication rated low (two or below) on the majority of questions. A low overall quality rating indicates that the publication is of 'poor' quality; it has serious shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and definitely should not be used.</p>

The instrument consists of 15 key questions plus an overall quality rating (on a five-point scale, of which five is the highest score) based on the answers to those questions. Each question represents an essential feature or standard that is an important part of good quality information on treatment choices. Instructions on using the tool are included on the DISCERN website – [discern.org.uk](http://discern.org.uk)

## Patient Information Forum (PIF)

The PIF is a social enterprise dedicated to supporting professionals in the provision of high-quality health information. The website provides basic advice about assessing health information. For more detailed guidance, you can order the PIF's *Guide to assessing health information*.<sup>2</sup> It covers:

- NHS requirements and the Information Standard
- tools for appraising printed information and websites
- readability
- online search strategies
- policy background and context.

The guide also includes a case study about Macmillan's approach to developing information resources. For more information, visit [pifonline.org.uk](http://pifonline.org.uk)

### References

<sup>1</sup> Charnock D, Shepherd S, Needham G, Gann R. DISCERN: An instrument for judging the quality of written consumer health on treatment choices. *Journal of Epidemiology and Community Health*. 2003; 53:105–111.

<sup>2</sup> Patient Information Forum. *Guide to assessing health information*. A PDF download is available online or printed copies are available to purchase. <http://www.pifonline.org.uk/themes/evaluating-the-quality-of-health-information/guide-to-appraising-health-information/> (accessed 24 October 2011).

# READABILITY TESTS

**Readability tests provide a quantifiable and objective assessment of how difficult or easy information is to read. They do not, however, assess whether sentences make sense, and they assume that words with fewer syllables are less complex, for example, 'axon' would be assumed to be less complex than 'furniture'.**

Readability tests have some drawbacks, including<sup>1</sup>:

- Most readability tests were developed for use with education materials for children, not for assessing health-related materials for adults.
- They don't allow for cultural differences in understanding of certain terms, such as 'borderline'.
- The tests cannot take into account the 'people factor' involved in reading, such as motivation, previous knowledge, gender, cultural background and age.
- Readability tests ignore the design factors that may balance out the use of some longer words or sentences.
- Readability tests are less accurate when used in shorter documents, and don't take into account that the shortest word may not be the most accurate.

The difficulty with applying readability tests to cancer information is that there is often a need for technical language that may increase the score. Even where lay alternative terms exist, users often need to have the medical term as well to assist them in consultations with medical staff.

## Interpreting readability scores

**Count** The number of characters, words, sentences or paragraphs.

**Average** The average (mean) number of sentences per paragraph, words per sentence or characters per word.

**Passive sentences** The percentage of sentences written in a passive voice.

## Readability age or grade

This is the reading level in years for an average person of that school year. Many readability tests use American school grade levels to describe the reading age. The rough UK equivalents are described below:

Age	Year at school England and Wales/Scotland and Northern Ireland	US school grade
9–10	5/P6	5 <sup>th</sup> grade
10–11	6/P7	6 <sup>th</sup> grade
11–12	7/S1 (secondary school)	7 <sup>th</sup> grade
12–13	8/S2	8 <sup>th</sup> grade
13–14	9/S3	9 <sup>th</sup> grade
14–15	10/S4	10 <sup>th</sup> grade
15–16	11/S5 1	11 <sup>th</sup> grade
16–17	12/Scottish Highers (sixth form)	12 <sup>th</sup> grade

## Flesch reading ease

The Flesch readability score<sup>2</sup> is well-known and can be run on many word processing packages. Three samples, each of 100 words, are taken from the beginning, middle and end of the document. The test computes readability based on the average number of syllables per word and the average number of words per sentence. Scores range from 0–100. Standard writing averages approximately 60–70. The higher the score, the greater the number of people who can readily understand the document.

### Interpreting Flesch scores

- 00–30 Very difficult (scientific paper)
- 30–50 Fairly difficult (academic paper)
- 50–60 Fairly difficult (quality paper)
- 60–70 Standard (digests)
- 70–80 Fairly easy (slick fiction)
- 80–90 Easy (pulp fiction)
- 90–100 Very easy (comics).



## The SMOG formula

The SMOG test (Simplified Measure of Gobbledygook) has also been in use for many years.<sup>3</sup> It takes a similar approach to the Flesch reading ease test that runs on your computer and it's simple to apply the formula to a piece of text. You can download concise instructions from the National Institute for Adult and Continuing Education website (<http://shop.niace.org.uk/readability.html>), which also has an online calculator. The SMOG formula is also discussed in a wider-ranging guide produced by the Patient Information Forum.

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### References

- <sup>1</sup> Patient Information Forum. *Guide to assessing health information*. A PDF download is available online or printed copies are available to purchase. Accessed: <http://www.pifonline.org.uk/themes/evaluating-the-quality-of-health-information/guide-to-appraising-health-information/> (accessed 24 October 2011).
- <sup>2</sup> Flesch R. A new readability yardstick. *Journal of Applied Psychology*. 1948; 32(3): 221–233.
- <sup>3</sup> McLaughlin GH. SMOG grading – a new readability formula. A new readability yardstick. *Journal of Applied Psychology*. 1948; 32 (3):221–232. *Journal of Reading* May 1969: 639–646.

# ASSESSING ONLINE INFORMATION

**Information about cancer is widely available on the internet. A Google search for 'cancer' produces hundreds of millions of pages. Even when the search is restricted to UK sites, it yields several million results. Much of this information may be misleading, out-of-date or irrelevant (such as pages about the zodiac sign 'Cancer'), but many sites do provide current research and helpful information on living with cancer.**

## Content

As anyone can claim to be anything on the internet, it's important to confirm that the website you are assessing was produced by the organisation with which it claims to be linked. Contacting the claimed organisation or producers of the site will help to confirm whether it's genuine. Good websites will also give information about their editorial policies, usually in the 'About us' section.

People will often assume that your use of a website in a cancer information and support service is a recommendation. It's therefore important to check the website's policy in relation to assessment of other websites to which it provides links, since users may assume that the linked resources are part of the 'recommended' website.

Sites that review their content regularly may vary the frequency with which different pages are updated, as some information changes more rapidly than other information. High-quality sites tend to give dates for the last review and the next review on each page.

## Presentation

Many websites include several thousands of pages of information. It's therefore important for people to be able to find their way around the structure. If people cannot find good content, it's a poor site. An assessment of a website's presentation therefore needs to include testing of the ease of finding information, including whether the links and search facilities work. Members of your advisory group may be able to help with this.

Website pages need to be kept short, as users will not always scroll down to the bottom. The website should also load with reasonable speed. If there are too many images or multimedia files to load, people may become frustrated.

Many people with visual impairment use text readers to help them to use the internet. The difficulty with text readers is that they tend to read across the page without taking account of columns. Complex displays with a number of text boxes could therefore come out as nonsense. Accessible websites will minimise the number of columns and include text descriptions of images (these may only be visible when you hold your mouse over an image).

Guidance on accessible websites for people with visual impairment is available from RNIB. Call **020 7388 1266** or visit **rnib.org.uk** Its website has a web access centre, a source of information for web designers, developers, content authors and website managers, including advice on how to plan, build and test accessible websites.

Free guidelines and training and assessment tools are available to help you appraise websites for yourself.

### Training

The Virtual Training Suite provides free internet tutorials to help you learn how to get the best from the web for your education and research. Visit **vtstutorials.co.uk**

### Advice from the British Medical Association

The British Medical Association (BMA) provides some advice on assessing the quality of health information online. The BMA website also provides an excellent list of links, leading to sources of high-quality information. Visit **bma.org.uk**

### Health on the Net

The Health on the Net Foundation (HON) has been a pioneer in establishing quality standards. The foundation's quality mark doesn't guarantee the medical accuracy or completeness of information on a website but it does confirm the publisher's commitment to ethical and transparent operation. The HON website is a useful starting point that offers search tools and information. Visit **www.hon.ch/home1.html**

### EQUIP

These links have been reviewed by NHS staff using recognised quality criteria. They are checked and updated regularly. Some of the materials are in languages other than English or are written in an easy-reading style. In addition to specific clinical topics such as cancer, the links include information on lifestyle, age and gender issues plus NHS and community services. Visit **http://nhslocal.nhs.uk**

### Check accessibility

You can run a basic check on a website's accessibility for people with a disability. A free tool has been developed by WebAIM, a non-profit organisation in the USA. It's a partnership between Utah State University and the Center for Persons with Disabilities. Simply paste the address for any web page into the WAVE evaluation tool at **http://wave.webaim.org/**

# CHECKLIST AND FURTHER READING

## Checklist

Reflect on identified need and resources available:  
number of items to hold, topics and levels



Establish an advisory group



Establish scope of the collection (subject range and format)



Establish inclusion criteria for information materials



Contact organisations and search databases for information materials



Identify national cancer-related information



Identify local information



Identify information that is not cancer specific



Obtain copies of materials for possible inclusion



Assess information materials against scope and inclusion  
criteria within acquisitions policy



Confirm information materials to be used by the service



Set date for next review of information materials



## Further reading

Faisal H, Read JC, Goodacre JA, et al. The role of quality tools in assessing reliability of the Internet for health information. *Informatics for Health and Social Care*. 2009; 34(4): 231–243.

McHugh SM, Corrigan M, Morney N. A quantitative assessment of changing trends in internet usage for cancer information. *World Journal of Surgery*. 2011; 35 (2): 253–257.

Gustafson DH, Hawkin R, McTavish F, et al. Internet-based interactive support for cancer patients: Are integrated systems better? *Journal of Communication*. 2008; 58(2):238–257.

Kandula S, Zeng-Treitler Q. Creating a gold standard for the readability measurement of health texts. *AMIA Annu Symp Proc*. 2008; 353–357.

Sawka AM, Straus S, Gafni A, Brierley JD, Tsang RW, Rotstein L, Ezzat S, Thabane L, Rodin G, Meiyappan S, David D, Goldstein DP. How can we meet the information needs of patients with early stage papillary thyroid cancer considering radioactive iodine remnant ablation? *Clinical Endocrinology*. April 2011. 74(4):419–23.

Wagner EH, Aiello Bowles EJ, Greene SM, et al. The quality of cancer patient experience: perspectives of patients, family members, providers and experts. *Qual Saf Health Care*. 2010; 19:484–489.

# 4

## MANAGING INFORMATION MATERIALS

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# IMPORTANCE OF MANAGING INFORMATION MATERIALS

**'Your role as an information provider is undermined if you can't find the right information when you need it.'**

Ruth Carlyle, Information and Support Policy Lead, Macmillan Cancer Support

## Basic principles of managing information



See 'Quality area 8: managing resources – indicator 5' of *MQuISS* in appendix 1.

It's important to spend time setting up clear information management systems.

When you are the only member of staff for a service, it's easy to set up a system that you can follow and then wonder why volunteers are unable to find information materials. If other people are able to understand the system, they will be able to better help you support people living with cancer more effectively.

This section will guide you through the basic information management principles as applied in cancer information and support services. A wide range of books and courses are available if you would like to study the subject in more detail.

Information about courses and details of current publications are available from the Chartered Institute of Library and Information Professionals (CILIP) and ASLIB, the Association for Information Management. Courses are also available from Task Force Pro Libra (TFPL).

### CILIP

7 Ridgmount Street, London WC1E 7AE

Tel 020 7255 0500

Textphone 020 7255 0505

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

[www.cilip.org.uk](http://www.cilip.org.uk)

The Health Libraries Special Interest Group within CILIP maintains a list of training courses with a specific focus on health at [cilip.org.uk/get-involved/special-interest-groups](http://cilip.org.uk/get-involved/special-interest-groups)

### ASLIB

Howard House, Wagon Lane,

Bingley BD16 1WA

Tel 01274 777700

Fax 01274 785201

Email [dheath@aslib.com](mailto:dheath@aslib.com)

[www.aslib.com](http://www.aslib.com)

### TFPL Ltd

2<sup>nd</sup> Floor, Chancery Exchange,

10 Furnival Street, London EC4A 1AB

Tel 0870 333 7101

Fax 0870 333 7131

Email [info@tfpl.com](mailto:info@tfpl.com)

[www.tfpl.com](http://www.tfpl.com)



# ALLOCATING SUBJECTS/ CLASSIFICATION

**The term 'classification' is used in library and information services to describe placing information materials on similar topics under the same subject heading so that they can be displayed together. This means that users of a service will be able to browse through information materials on a similar topic, without always having to refer to the catalogue or full listing of information.**

## Using non-threatening subject headings

There are several classification schemes available but most public libraries use the Dewey Decimal Classification scheme. Dewey is a general scheme covering what in the 19<sup>th</sup> century was regarded as the whole of knowledge. As the name suggests, Dewey Decimal Classification uses numbers to represent subjects. This enables librarians to insert subsections after the decimal point.

Looking at information in your local public library will give you an example of how information has been classified. It will also give you an insight into what cancer information is available locally. Information about medicine can be located in section 61. You are likely to find information on cancer and health under 613, although cancer may also be under 616 'internal and clinical medicine'. Different aspects of living with cancer may be coded separately, so caring may be under 362, bereavement under 301 or 155 (children) and benefits under 368.

Cancer information and support services, including the Mobile Macmillan Cancer Information Centres, tend to use colours and words for the main subject headings. These are then linked to underlying codes for each item. The individual codes help to keep the information materials in order, so that they can be found or 'retrieved'.

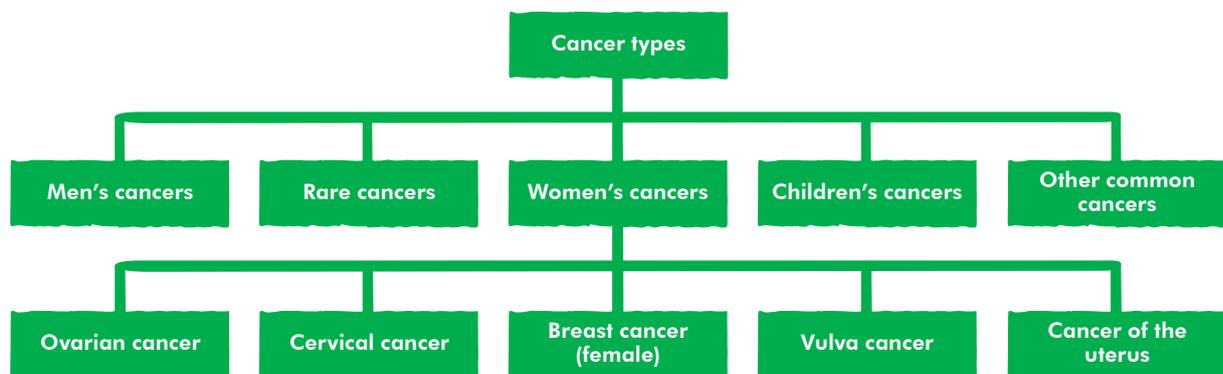
The classification codes/subjects tend to be less threatening if the language used reflects that of service users, eg 'Men's cancers' and 'Women's cancers'.

## Classification as a total system

It's possible to insert categories into a classification scheme as the service grows, but you don't want to spend time recoding information materials unless absolutely necessary. It's important to think clearly about the total structure in the context of the scope of your collection.

It's particularly important to have a clear sense of how the different categories relate to each other. Librarians refer to the thesaurus structure for the classification scheme, with 'broader' and 'narrower' term relationships. If you are thinking about creating a new system, consider asking a local librarian or information specialist to advise you.

The diagram below gives shows broader and narrower terms in a thesaurus structure, with cancer types as the broadest term. Each cancer type could have narrower terms for different aspects of living with that cancer type.



## Reflecting the physical location in the classification code

Information materials are classified so that they can be found when they are needed. The classification used therefore needs to reflect the physical grouping of information materials as well as the topic. This is particularly important if you are using the basic tiers of introductory, main display and detailed information. Signs on the main display need to indicate that further information is available and the coding should enable staff or users to find the additional information easily.

## Example of classification from Mobile Macmillan Cancer Information Centre catalogue

### CancerSearch Keywords – Macmillan Cancer Support Macmillan mobile cancer information centre classification

Topic	Code
Introductory display (cancer and general information on services)	X
Risk factors	A
Screening and diagnosis	B
Treatments and therapies	C
Treatment side effects	D
Using health services	E
Women's cancers	F
Men's cancers	G
Children's cancers	H
Other common cancers	I
Living with cancer	J
Relationships	K
Caring	L
Money matters	M
Loss and bereavement	N
Information for children	O
Non-English language	P
Reference	R
<ul style="list-style-type: none"> <li>• Cancer management</li> <li>• Medical reference</li> <li>• Living with cancer</li> <li>• Source of support</li> </ul>	

The same classification is used for main display and reserve/back room stock, but main display items are coded M and back room stock B, eg AM3 would be a leaflet on risk factors in the main display, KB2 would be a leaflet on relationships in the back room only.

# MARKING INFORMATION MATERIALS

**Having established the order that information materials should be displayed, the materials and display racks need to be labelled. Labelling makes it easier to keep information materials in order. Resources for reference or loan also need a mark of ownership and a unique identifier.**

## Mark of ownership

If the item is to be kept by the information service and available only for reference or on loan, it will need to be marked to indicate that it's owned by your service. Usually, a stamp is made up with the name of the service. This might be used along the edges, on the cover or on the inside, depending on the format. Alternatively, pre-printed labels can be used – these are less permanent, but are useful for shiny covers that will not take ink.

## Accession numbers

One of the terms you will come across in information management publications is 'accession', either in the context of accession numbers or accession lists.

There are times when it's important to be able to distinguish between different copies of the same resource. If you run a loan scheme, for example, you need to know which copy a user has borrowed in case it isn't returned. The unique identifier used in most libraries and information services is the accession number.

Every time a new item is acquired, it's given an accession number – the first item to be acquired is '1', the second '2' and so on throughout the life of the information service. Sometimes the number is formatted so that it's clearly an accession number, for example 'ACC00741'. Depending on the format of the information, the accession number is usually written on the title page or on the front of the cover.

Some information services keep an accessions list as part of the process of checking on orders. This is a listing of information materials held in the order that they were acquired. If you are using a software package or spreadsheet, the accessions list can be generated from the catalogue entries.

## A typical accessions record

Accession number	Author	Title	Publisher	Publication date	Price	Supplier	Date received
1							
2							
3							

## Classification labelling

Classification labels indicate the place where a particular item is displayed or stored. It is therefore important for the labelling to be clear. If you have opted for colours and word headings, use coloured labels with the classification category, for example 'Women's cancers', in full at the top of the label and the code for the individual item, for example 'FM4', underneath. Adhesive labels tend to peel off unless they are covered and ordinary sticky tape turns yellow and cracks. Details of specialist suppliers are available through the buyers' guide on the website for the Chartered Institute of Library and Information Professionals ([buyersguideonline.co.uk](http://buyersguideonline.co.uk)) or you can buy Scotch® tape from most stationers. Rubbing the tape over the label with the handle of a pair of scissors forces air out and results in a more permanent seal.

It's usual practice to place classification labels on information available for reference or on loan from the service, but not information materials that people can take for their own use. You may wish to place labels with contact details for the service on the back of leaflets people can take away, in case they want to come back for more information or support.

Some services choose to retain one copy of each leaflet for reference use in the centre only. This means service users will always have access to the full range, even if they are not able to take information away.

Leaflets and booklets in the main display can be kept in order more easily if the racks are labelled as well as the leaflets. Labels are particularly useful behind leaflets people are able to take for themselves, as you cannot always guarantee that users will leave the last copy as a guide for future restocking.

### Typical label behind display materials:

- classification (subject)
- title of publication
- publishing organisation/author
- code
- additional information is available on this topic
- please ask for details.

# LISTING MATERIALS/ CATALOGUING

**A catalogue is a list of resources held by an information service. It's a key tool within the service, as it will enable you to find information materials when you need them.**

## Functions of a catalogue

The catalogue fulfils several different functions. It's firstly a listing of the materials that you hold, with sufficient information for you to be able to re-order copies of information. It's also an asset register for the service. Keeping a copy of the catalogue off site, even if it's just a print-out at home, helps to protect the service in the event of fire or flood, as you will be able to provide information for your insurers and reorder materials relatively quickly.

In addition to its role in resource management, a catalogue also provides staff, volunteers and more confident users with a tool to identify and find information held by the service on particular topics.

The *Materials starter kit* list of suggested information materials is available as an excel spreadsheet, which can be adapted for use by cancer information and support services. For a copy, contact the Information and Financial Support team on **020 7840 7829** or email **[infomanager@macmillan.org.uk](mailto:infomanager@macmillan.org.uk)**

## Minimum fields for a catalogue

The catalogue needs to hold sufficient information for you to be able to find the precise copy of the publication listed, order additional copies and find information on a topic when you don't know the title of the best publication to use.

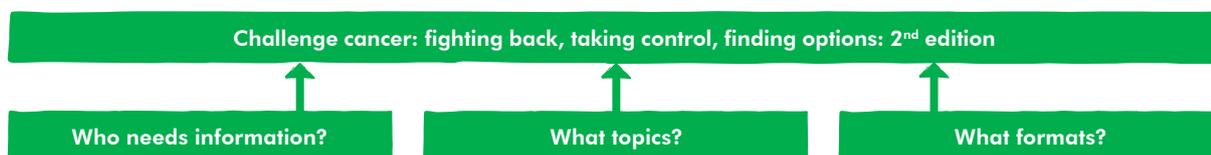
## Typical minimum fields for a catalogue

Accession number	001	002	003	004	005	006	007
Author							
Title							
Publisher							
Date							
Classification							
Cost							
Keyword 1							
Keyword 2							
ISSN/ ISBN							
Format							
Language							

**Accession number** The unique identifier for each copy of a reference or loan publication.

**Author** For consistent listing, the authors’ details will need to follow an agreed pattern. The standard format in most catalogues would be ‘SMITH, John’ or ‘Smith, J’. Catalogues usually list up to five authors.

**Title** The titles of the publications. It’s important not to place the definite article (the) or an indefinite article (‘a’ or ‘an’) as the first word in the title, since this may confuse any alphabetical listing by title. The entry for Macmillan’s booklet, *The cancer guide*, for example, would therefore appear as ‘Cancer guide, the’ in a catalogue entry. *The cancer guide* will then appear under ‘C’ for ‘Cancer’, not ‘T’ for ‘The’, in an alphabetical list. Some catalogues also include series titles, subtitles and editions as separate fields. To include a subtitle and edition in a single title field, format as follows:



**Publisher** The name of each publisher needs to be entered consistently.

**Date** Most services just give the year although the month may be useful for distinguishing between different editions, particularly for resources that are updated frequently. It's important to decide this at the outset.

**Classification** The individual classification code for the publication. It's the most important field in the catalogue, as it enables people to find the listed item on the shelves.

**Cost** A useful field for budget management and the asset register.

**Keywords** These are valuable additional terms for cross-reference as a single copy of a publication can only be filed in one location following your classification scheme. Like classification, you need to have a structured keyword list.

**ISBN/ISSN** Books and journals have unique identification codes to help with re-ordering. These are the International Standard Book Number (ISBN) and International Standard Serial Number (ISSN). The grouping of the numbers within the code varies and does make a difference, so it is worth watching hyphens/spaces in the layout of the numbers.

**Format** The format of the publication, for example, leaflet, video or Braille.

**Language** The language that this copy of the resource is produced in.

**Stock quantities** The number of copies held and order dates need to be linked to the catalogue, but are not part of the catalogue for public display. A linked table in a database is ideal. If not, columns in a spreadsheet can be hidden from the display.

## Format for the catalogue

Ideally, the catalogue for the service should be available to users of the service as well as to staff and volunteers. It needs to be presented in a format that is useful to people.

If you don't have a database, for example in Microsoft Access, to run your catalogue, a spreadsheet program such as Microsoft Excel will give you options to print out your catalogue in different ways. Using a standard spreadsheet with the minimum recommended headings for a catalogue, you can select different columns and print out the list in alphabetical order by title and keywords.

Guidance on how to use the catalogue to find information should form part of your guide to the information service.

# STOCK MANAGEMENT

The information materials you carefully selected for your service are a valuable resource. The processes for looking after the stock you hold are therefore an integral part of the service.

With clear procedures, much of the day-to-day management of information materials can be delegated to volunteers. Many volunteers enjoy having definite roles in information management.

## Regular stock management tasks that volunteers may wish to be involved with

Task	Frequency
Checking information materials are in order	Weekly/fortnightly
Counting numbers of leaflets used	Weekly/fortnightly
Re-stocking leaflets in display from store cupboard	Weekly/fortnightly
Ordering replacement information materials	Monthly
Mark of ownership on books and videos	Ongoing
Stickers on leaflets to show that they came from the centre	Ongoing

## Keeping materials in order

As the whole process of information management is focused on ensuring that information materials are displayed in logical subject classifications, it's important to ensure that racks and shelves are kept in order. While staff or volunteers are checking that information is in order, leaflet dispensers can be also be checked and re-stocked if supplies are running low.

In the cancer information and support service at Queen Alexandra Hospital, Portsmouth, volunteers routinely check that leaflets are in order and restock the dispensers. An administrative volunteer notes when stocks are running low and orders new supplies from [be.macmillan.org.uk](http://be.macmillan.org.uk)

At the Delamere Centre at Halton Hospital, Runcorn, the Macmillan information assistant is responsible for checking the information materials.

## Reserve stock levels

For ease of checking stock levels and re-stocking the main displays, reserve supplies of information materials need to be stored in the same order as the display (the classification order). Investing in partitioned boxes, such as cardboard pigeonholes, may make it easier to keep information in order within a confined space.

The boxes/partitions for the reserve stock should be labelled in the same way as the main display, with the title and classification code, in case the last copy of a publication has been taken.

Counting reserve stock on a weekly basis can be time-consuming. If you don't have the resources to arrange for a precise count, try placing a marker above the minimum stock level to trigger the re-ordering process without the need for a precise count. You can reduce the need for counting by storing copies in bundles. For example, keep leaflets in groups of 10, bound together by a rubber band.

## Re-ordering leaflets and booklets

The minimum stock level for re-ordering publications will vary according to the volume you use. The time taken between order and receipt of publication varies by supplier, but allow for a six-week turnaround when setting your minimum stock levels.

Most suppliers will accept a signed fax as an order and then send an invoice with the stock. You may find it easier to place orders using the forms produced by individual suppliers. Some suppliers may require cheques with orders.

It's important to follow the local policy if there is one place. If you are working within an NHS Trust, you may need to have order numbers for each order placed. Some Trusts set up ordering arrangements with suppliers and then provide information service managers with a card and reference number to show that they are entitled to place orders.

## Ordering Macmillan resources

You can browse Macmillan's resources and order copies free of charge at **[be.macmillan.org.uk](http://be.macmillan.org.uk)** or by calling **0800 500 800**.

## Providing information on loan

Some people who use cancer information and support services prefer to read or look through information materials in the privacy of their own homes. In particular, people like to be able to watch DVDs or use other non-print information materials at home. You will therefore need to set up a loans system.

A loans system need not be complicated, as long as you know which copy is where and can contact the user to ask for it to be returned. Some services have a definite loan period, for example, users of the service can borrow information materials for three weeks. Most people will adhere to the loan period, but you will need to be able to check which items have been out for more than the loan period, so that you can contact people to ask them to return items.

If you are able to link information about loans to your catalogue, you and your volunteers will be able to see which items are out on loan when searching for information on a particular topic or checking that the information in the displays is in order. Alternatively, some services just keep index cards in alphabetical order by title and flick through them quickly. If you are using a card index in title order, you will need to keep a separate record for each user of the items they have on loan. Most services do not have problems with users returning loaned items.

# KEY COPYRIGHT ISSUES

**It's important to be aware of your copyright responsibilities, as the penalties for breaching copyright can be very heavy.**

## What is copyright?

It's an unregistered right that protects forms of expression – it doesn't protect ideas and concepts. The law of copyright is covered by the UK Copyright, Designs and Patents Act 1988 (as amended) (CDPA) and protects the copying of protected material in any medium.

**See 'Quality area 8: managing resources – indicator 6' of *MQuISS* in appendix 1.**

## Who does it protect?

Copyright protects the rights of the owner of the copyright. The general rule is that the creator or author of the work will be the first owner. This is different where the work is produced by an employee in the course of their employment, in which case the employer is the owner. However, if you are using volunteers, you should be aware that they are first owners and you will need to transfer any rights.

In the UK, copyright exists automatically and doesn't need to be claimed.

## Stating copyright

Because copyright exists automatically in the UK, there is no regulatory body to apply to for protection but including a statement would help to enforce your rights, eg © Macmillan Cancer Support, 2011.

## Length of ownership

How long copyright lasts depends on the type of copyright work. Protection for written, theatrical, musical, and artistic works is for the life of the creator plus 70 years. It's different for sound recordings and broadcasts, which last for 50 years from the end of the year that the recording/broadcast is made, and protection for the typographical arrangement of a publication lasts for 25 years from the end of the year the edition was published.

## Infringement and rules for copying extracts

Copyright is infringed if, without the consent of the owner, a person copies or issues copies of the work, rents or lends it to the public, performs or plays it in public, communicates it to the public or makes an adaptation of the work or a substantial part of the work. The significance of the extract copied in relation to the work as a whole is also taken into account in determining what is a 'substantial part'. This is based on what has been copied, not how much has been copied.

Some organisations encourage the use of their information but you'll need to check for any restrictions. For example, the reproduction of certain material, which would normally be subject to Crown copyright, may be allowed under the terms of the Open Government Licence. For more information, visit [nationalarchives.gov.uk/doc/open-government-licence](https://nationalarchives.gov.uk/doc/open-government-licence)

### 'Fair dealing'

If material is reproduced for non-commercial research or private study, criticism or review, or for the reporting of current events, it may be considered 'fair dealing' and so may be permitted. This is provided it's genuinely and fairly used for the stated purpose and is accompanied by a sufficient acknowledgement. However, any copying for research or private study that is carried out for commercial purposes doesn't fall within the 'fair dealing' exemption.

## Getting clearance to use copyright material

It is important not to copy any material without permission, unless you're covered by an exception under the CDPA. If you are unsure whether you are covered by an exemption then it's advisable either to ask for permission or get advice.

For published material, you can normally get permission for use from the publisher and their contact details are often found on the publication itself. There may be a cost involved and you may need to get permission each time you use the material but this is at the discretion of the person granting permission and can be agreed with them.

Depending on the amount of material you wish to reproduce and how often, it may be more beneficial to take out a licence from a licensing society such as the Copyright Licensing Agency ([cla.co.uk](https://cla.co.uk)). If you're reproducing copyrighted material in the course of your employment, it's worth asking your employer if they have already obtained such a licence.

## Electronic resources

Information downloaded or printed out from an electronic database or website is covered by copyright in the same way as material in other media. So you should always think about whether you need permission from the copyright owner.

If you are creating a database, it may attract database rights.<sup>1</sup> These rights arise automatically when a database is created. Database rights last for 15 years from the date the database is created or from the date of publication if it's published during this time. It's possible for databases to attract protection as a literary work and longer (70 years – see above). The same considerations about permission still apply to database rights.

## Visually impaired users

The CDPA also allows you to make an accessible copy (Braille, large print, audio, screen reader compatible) of a document for someone with a visual impairment for their personal use. This is provided that the publisher hasn't produced a large print version. The copy must be accompanied by a statement that says it has been made under s31A CDPA and it must acknowledge the title and author.

There are other exceptions that may be relevant. For more information, visit [ipo.gov.uk](http://ipo.gov.uk)

### Further information

The Copyright Licensing Agency takes enquiries on copyright issues through its website – [cla.co.uk](http://cla.co.uk) Additional information is available from the Intellectual Property Office website – [ipo.gov.uk](http://ipo.gov.uk)

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### Reference

<sup>1</sup> The Copyright and Rights in Databases Regulations 1997.  
[www.legislation.gov.uk/uksi/1997/3032/contents/made](http://www.legislation.gov.uk/uksi/1997/3032/contents/made) (accessed 24 October 2011).

# USER GUIDES AND MANUALS

**People who use your cancer information and support service need to know what information you offer and how to find it. The distinction between content for user guides and manuals for staff or volunteers will vary by service, but guidance is needed on the information available and procedures for managing the service.**

## User guides

The level of detail in the user guide will need to be agreed with your steering group or information materials review group. If you have a good promotional guide for the service, you may decide not to produce the user guide as a leaflet, but as a poster or (very briefly) as a bookmark.

### Possible topics to be covered by a user guide

**Location of service** For many services, this will be covered by promotional materials, but you may wish to go into more detail about the location and availability of the information area within the cancer information and support service.

**Layout** The placement of information – particularly the introductory information, main display and the availability of more detailed information. Users of the service should know where to find public access computers and telephones, and where they can request copies of leaflets while at the centre. You may choose to show which subjects are covered where in the layout.

**Subjects covered** The range and type of information available in the main categories of information within the service.

**Services available** Outline the range of services available, such as information materials available on loan, information leaflets, guided access to information in answer to questions, guided internet access, and someone to talk to about living with cancer.

**Finding information** Provide guidance on how the system works (and the catalogue, if it's available to users).

**Support from staff and volunteers** Outline the ways that staff and volunteers can help users of the information service and how to contact them.

If people are aware of the range of information and services available through the information service, they are more likely to use it or to suggest the service to others.

## Manual for the information service

Information services must be consistent, so that people can find information when they need it. Maintaining a manual on how the service is run provides a training and reference point for volunteers. It also helps the service manager to delegate responsibilities for particular aspects of the service, as overall procedures are clear. If you have an operational policy for the service, this should form the basis of the manual.

The manual will be a growing document, evolving and changing as the service develops. Setting dates to review the different sections will help you to keep the contents up-to-date. Most services keep a paper record, usually an A4 folder. An electronic folder containing all the different parts of the manual also eases the updating process.

### Possible topics to be covered within your manual for the information service

**Collection policies** Acquisitions policy (scope and selection criteria); loans policy.

**Classification system** Categories and guidance on how to allocate information materials to different topics.

**Keywords Lists** of keywords and guidance on their use.

**Cataloguing procedures** Standard formats for inputting text in each field, guidance on frequency of printing out catalogue

**Stock management procedures** Arrangements for ordering materials, marking of information materials, stock control, re-ordering and loans.

**Catalogue printout** List by classification, list of information materials by keyword, list by title.

## Maintaining the management of information materials

Regular reference by all staff and volunteers to the manual for the information service will help you to maintain the management of the information materials within your service.

Once systems are in place, they save time and improve the quality of the service provision, as all those involved in the service can find information when it is needed.

**If you need support with managing information materials, contact the Information and Financial Support team on 020 7840 7829 or email [infomanager@macmillan.org.uk](mailto:infomanager@macmillan.org.uk)**



# CHECKLIST AND FURTHER READING

## Checklist

Select/develop classification headings



Select/develop codes for individual materials, reflecting the physical location



Develop cataloguing system



Allocate information materials to classification headings and code



Mark information materials: ownership; classification heading and code (accession number if used)



Label shelves: location of individual materials and subject headings



Catalogue information materials



Set up systems to check information materials are kept in order



Set up minimum stock levels and re-ordering arrangements



Set up loans scheme for information materials



Train volunteers on copyright restrictions



Develop guide for service users



Develop and maintain manual for the information service



## Further reading

Bandy M, Dudden R. *The Medical Library Association guide to managing health care libraries*. 2011. Neal-Schuman Publishers Inc. ISBN-13: 978-1-55570-734-7.

Jankowski T A. *The MLA essential guide to becoming an expert searcher: Proven techniques, strategies, and tips for finding health information*. 2008. Neal-Schuman Publishers Inc. ISBN-13: 978-1-55570-622-7.

Robinson L. *Understanding healthcare information*. 2010. London, Facet Publishing. ISBN: 978-1-85604-662-6.





# PROVIDING CANCER INFORMATION

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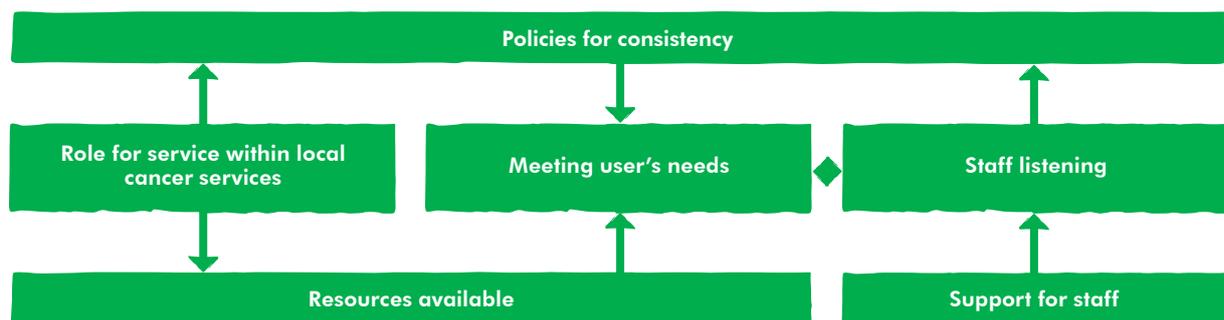


# INTRODUCTION

**'It's a minefield out there and really confusing for cancer patients. I wanted to feel assured that I had the best information available so I could go to a consultation with my doctor with something he'd be happy to discuss.'**

Person with cancer, 2010

## Providing cancer information well



Over the past few years, some aspects of providing cancer information in the NHS have changed dramatically. Understanding these new developments is crucial for people managing cancer information services.

The emphasis is very much on responding to the individual, with the aim of providing the right information, at the right time and in the right level of detail. Information should be selected in a consultation between the patient and/or carer and a professional, and it should match the needs of the individual at that particular point in time. Another way to think of it is providing the information that is most likely to be valuable and relevant to the person on the day of the consultation.

You will find more information about two important developments – cancer information pathways and information prescriptions – **on pages 111–113**.

Many people concerned about or diagnosed with cancer will not be familiar with the NHS or cancer services. It's important to make time to help them identify their questions, without making assumptions about previous knowledge or current needs. People using the service need to feel confident that the staff and volunteers have the skills and time to provide this support.

Sound policies are important to provide a consistent basis for service provision. They need to be combined with training so that staff and volunteers have excellent communication skills, treat personal information confidentially and are non-judgmental in their approach to people from all backgrounds.

# HANDLING CANCER INFORMATION ENQUIRIES

The range of ways that people make enquiries will depend on how you have set up your service. The same basic principles apply to handling enquiries received in person, by telephone, letter or email, but it can be harder to identify the underlying information needs of someone who is not visiting the service.

See 'Quality area 4: user-centred service – indicator 5' of *MQuISS* in appendix 1.

## Beginning the enquiry

It's important for staff and volunteers to be approachable. Let the user know who you are and what the service offers. Make sure you are on the same physical level as visitors – both either sitting or standing – with open body language (arms shouldn't be folded and it's natural to lean towards someone if you are listening to them).

If you are taking notes, explain to the user that they are to help you to work out what information would be most appropriate and for general statistics on usage of the service. Taking notes should not distract from the discussion.

## Explore the content of the enquiry

Many people are not sure exactly what they want and need help to tease out the issues that are worrying them. Acknowledging the emotional impact of cancer on all those affected can help people to open up, particularly if it's clear that additional emotional support is available.

## Use open questions can help users to raise their concerns

'How do you feel about...?'

'How do you think you will cope between now and your next appointment?'

'How helpful did you find...?'

Choosing the same words as the service user can help to build rapport. You may need to ask what the person means by words they are using as you explore their questions, to be sure you understand them and that they have understood any medical terminology.

## Clarify and summarise

Before suggesting options for information and support, you need to be sure that you have interpreted the needs of the user correctly.

### Summarising issues

**'So, Mrs Brown, I understand that, although you are worried about the possible side effects of chemotherapy, your priority at the moment is information about travel insurance and possible financial help so that you can plan a visit to your son in Sydney. Would you like me to talk through the options for your visit with you?'**

When there are several complex issues, prioritising initial concerns can make the enquiry more manageable for the service user as well as the service provider. Acknowledge the full range of issues and ask whether the user is happy for you to concentrate on suggested questions. It's important not to make assumptions about which issues are of most concern to the service user.

## Guide user through range of options

Consider the most appropriate options, support needs, information received previously by the user and the resources available within your service and other specialised services. To help the user to decide which services or resources are most appropriate for them, go through the benefits and possible limitations of each option.

**See 'Quality area 4: user-centred service – indicator 6' of MQiISS in appendix 1.**

## Ending the enquiry

All enquiries need to have a clear ending, regardless of the level of complexity of the issues raised. It can sometimes be helpful to put a time frame on the end of the enquiry, such as: 'During the next five minutes or so we'll go through what we have just discussed and any comments or suggestions, then I'll leave you to look through the resources in the centre'.

## Summary of stages in providing cancer information

**Beginning** Listening to user's concern.

**Explore the content of the enquiry** Establish the real issue of concern (may not always be the opening question) and any information previously received on the topic.

**Clarify and summarise** Clarify question.

**Guide user through range of options appropriate to them and their query**

- Introductory information.
- Published leaflets or non-print resources.
- Detailed resources, such as published papers.
- Guided internet search.
- Listening support.
- Counselling.
- Specialised services offered elsewhere (signposting).

**Identify how to end and clarify user's choices** Check that the question has been answered, confirm options and ensure user knows that they can come back to the service.

## Written enquiries

When you can see someone, it's easier to judge whether they are in distress or whether they have understood. On the telephone, you have the opportunity to reflect back issues to ensure that you have understood, but it can still be hard to judge emotion or understanding. Letters and emails often present you with very little background about the enquirer's situation.

If someone contacting the service by email or in writing gives their telephone number, ring them so that you can clarify their information needs. Don't be tempted to overwhelm the enquirer with what you think they need, but provide sufficient information and further sources for them to take the next steps themselves or come back to you if they prefer.

When replying to email, you have the opportunity to include links to websites or files. Once you have established the enquirer's needs, this can be a very productive mechanism for providing information.

# POLICIES FOR YOUR CENTRE

**The purpose of a policy is to ensure consistency. Policy documentation doesn't need to be lengthy, just clear and understood by everyone involved in running the service.**

## Confidentiality

Personal information supplied by users is usually confidential to the service. This is any information that identifies an individual, not just their name and address. If not, disclosing information will result in harm to the individual or others. The service needs to have recorded procedures for who should be involved in the decision to disclose information, and how the disclosure should be recorded. Data on enquiries should be anonymised when provided to anyone outside the service.

**See 'Quality area 8: managing resources – indicator 8' of *MQuISS* in appendix 1.**

## Data protection and Caldicott guardians

The Data Protection Act 1998 covers records by which living individuals are identifiable, such as address lists. Every organisation should be registered with the Information Commissioner ([ico.gov.uk](http://ico.gov.uk)) to hold specified types of information. Under data protection, you need to inform people that you are taking their names and addresses and how the data will be used and give them the option not to have their details held. For example, to send out evaluation forms or invite them to events, but not to supply details to other organisations. Data protection covers information in all formats, not just electronic records.

'Caldicott guardians' ensure that the data held is justified by the purpose for which it is collected, and that systems are in place to minimise the risk of breach of confidentiality. They take their name from a committee chaired by Dame Fiona Caldicott, which reviewed the use of patient identifiable information within the NHS.<sup>1</sup> A Caldicott guardian should be able to advise you on data security policies.

## Medical information

The service's policy needs to distinguish between medical advice provided by clinical staff and information provided by the service. Users of the service may not be fully aware of their diagnosis or the implications of their treatment choices. In a supportive non-directive environment, services may suggest that users contact their doctor or medical team, but shouldn't refer people to a clinical service unless they are part of the same clinical setting and have established specific links for referral.

Part of the service's policy on medical information should cover users who are concerned about symptoms that may be indicative of cancer, but don't have a cancer diagnosis. Services are well-placed to provide guidance on the questions users should ask their doctor, but are unable to provide diagnostic support.

## Informed consent

Information and support services have a role in providing information to help inform decision-making, but not responsibility for informed consent to medical treatment. Changes in informed consent guidance for the NHS<sup>2</sup> mean that records of when particular information materials were supplied to patients can form part of the informed consent process.<sup>3</sup>

If your cancer information and support service is within a clinical setting, you will need to identify the person responsible for informed consent procedures within the Trust and clarify their expectations of the role of the information service. Local policies will vary, so it's important to check.

## Use of online information sources

The service has a range of options for using online information sources, but needs to have a consistent policy.

Options for use of online resources include:

- guided access for individual service users to the internet and other databases, with advice on judging data quality
- a suggested list of sites and databases for individual users to search
- a suggested list of sites to be searched by staff and volunteers on the behalf of users.

**See 'Quality area 8: managing resources – indicators 6 and 7' of *MQUISS* in appendix 1.**

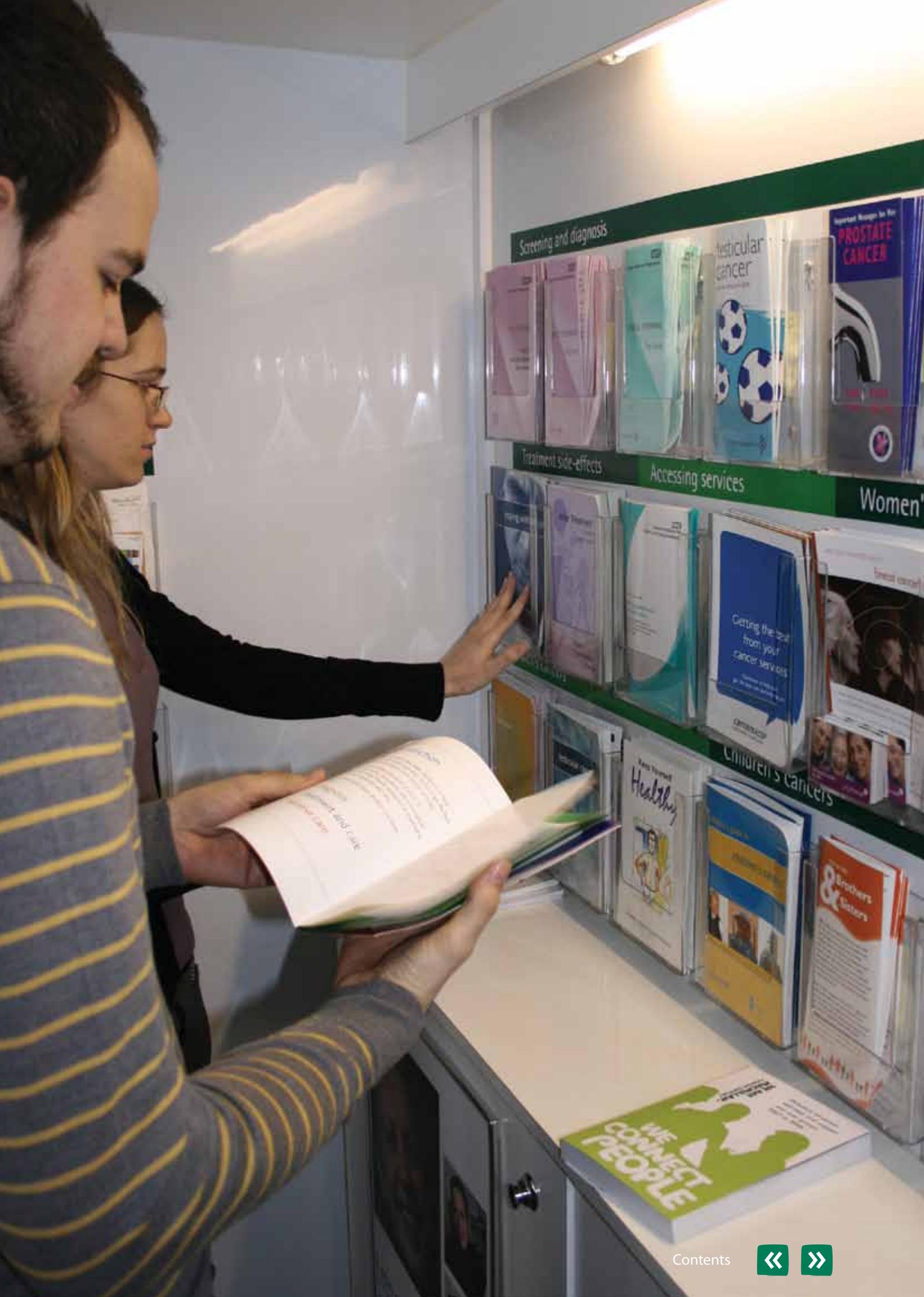
## Sending out information

When sending out information, whether by email or post, how professional the communication is will contribute to the perception of your service. The policy for sending out information should include a personalised response and use of email footers, letterhead paper/compliment slips, dating and referencing of information sent. The service also needs to have a policy on requests made by one person for information to be sent to someone else ('third party' requests). Most services will only send information to the person requesting it. Unless you have been in contact with the person directly, you cannot be sure that the information is appropriate. Some services will send information to a third party at the request of a health professional, but not friends or relatives of the enquirer.

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### References

- <sup>1</sup> Department of Health. The Caldicott Committee. *Report on the review of patient-identifiable information*. 1997. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4068403](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4068403) (accessed 24 October 2011).
- <sup>2</sup> Department of Health. *The NHS Plan: a plan for investment, a plan for reform*. 2000.
- <sup>3</sup> General Medical Council. *Consent: patients and doctors making decisions together*. June 2008.



Screening and diagnosis

testicular cancer

Important Messages for Men  
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WE CONNECT PEOPLE

Contents



# PROVIDING PERSONALISED INFORMATION

**Providing personalised cancer information has become firmly established as best practice. National initiatives, which Macmillan is taking a leading role in, now provide you with a core of reliable information resources that can be clearly matched to your service user's needs at a given point in time. This approach can also ensure that people affected by cancer receive consistent information from the various professionals they consult.**

There are two main areas of work to be aware of:

- National cancer information pathways
- NHS information prescriptions.

These are separate but closely related topics so each is discussed here in turn.

## Cancer information pathways

The stages over which a person becomes aware that they have a health problem, through diagnosis and treatment, are often referred to as their 'cancer journey' or their 'pathway' through the cancer services system.<sup>1</sup>

The National cancer patient information pathways make 'nationally agreed information available to front-line cancer health professionals, enabling them to offer it to their patients at key points in the cancer journey.'<sup>2</sup> The information for each stage is presented in short electronic documents, which are tightly focused on the person's immediate query. Providing information in small bursts like this can be especially helpful when a patient is having trouble taking in information or is coming to terms with their diagnosis and is not emotionally ready to take in the entire picture.

Each nation is developing its own approach to cancer information pathways.



## England

In England, work on new information pathways has been intensive over the past couple of years and is led by the National Cancer Action Team (NCAT). There has been active user involvement in the development of these resources. Macmillan is one of the voluntary sector partners in this project and our publications account for much of the information on offer.

These new pathways have been piloted and national implementation is in progress. Information on most tumour types is now available to include in information prescriptions.

Some of the pathways are tumour-specific. For example, pathways for breast, bowel and prostate cancer are just a few that are already well-developed. Other pathways, such as palliative care, are more generic.

### Stay up-to-date on pathways

#### National Cancer Action Team

[www.cancerinfo.nhs.uk](http://www.cancerinfo.nhs.uk)

Checking this website from time to time will help you stay current and see what new pathways are available. The National Cancer Action Team's patient experience website acts as the site for reviewing new and existing information pathways.

## Scotland

The cancer information pathways developed in England are being considered for adoption in Scotland. Some of the pathways will be piloted to test whether they work well for patients, carers and professionals in NHS Scotland, and whether the information should be adapted for local needs.

## Northern Ireland

The pathways originally developed for England are being used in Northern Ireland, with some adaptations. Information about welfare benefits has been changed to reflect the different system in Northern Ireland. There are ongoing discussions about how best to deliver the information to patients and carers.

## Wales

A separate mapping exercise has taken place for information pathways in Wales. Part of the aim has been to engage professionals locally about what should be offered and when. This work is also feeding into development of the new health information strategy for Wales.

## Information prescriptions

Just as a prescription for medicine gives people the treatment they need for their condition, information prescriptions provide reliable facts to help them make choices, manage their health and maintain independence.<sup>3</sup>

The NHS Choices Information Prescription Service was designed to help people with a range of long-term conditions, including cancer. You can use the online tools to generate an individualised information prescription for a person using your service. The information prescription can provide details about social care topics and local cancer services, as well as clinical facts. There is also a mechanism that allows professionals to record the information prescription history for an individual.

People can also use the NHS Choices website – [nhs.uk/ips](http://nhs.uk/ips) – to generate their own information prescriptions for cancer. They can save an electronic record of these self-generated information prescriptions if they wish.

To give people even more control over their own health and cancer care, many localities now offer patient-held records. You can encourage your service users to note the details of any information they receive – or access themselves – in this record for future reference.

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### References

<sup>1</sup> National Cancer Action Team. *Glossary of terms*. [www.cancerinfo.nhs.uk/component/glossary\\*/#Keypoints](http://www.cancerinfo.nhs.uk/component/glossary*/#Keypoints) (accessed 24 October 2011).

<sup>2</sup> National Cancer Action Team. *Patient Information: the challenge*. <http://www.cancerinfo.nhs.uk/healthcare-professional/patient-information> (accessed 24 October 2011).

<sup>3</sup> NHS Choices. *Information Prescriptions Service. User guide for health and social care professionals*. Version 2. July 2011.

# CHECKLIST AND FURTHER READING

## Checklist

Set up procedures for handling cancer information enquiries

Develop training on handling cancer information enquiries

Set up debriefing and support for staff/volunteers

Develop confidentiality policy

Check record keeping is within data protection and Caldicott guidance

Develop policy on medical information

Confirm whether the service has a role in local informed consent procedures

Develop policy and training for use of external information services

Develop policy for sending out information

Liaise on role of service within local cancer information pathway

Set up monitoring of enquiries

Establish role in information prescription pathway

Establish review systems

## Further reading

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Kinnane NA. Evaluation of a hospital-based cancer information and support centre. *Supportive Care*. 2011; Jan 13. [Epub ahead of print]. DOI: 10.1007/s00520-010-1071-y. Access at: <http://www.springerlink.com/content/q7231q100p581783/>

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Robertson LM, Douglas F, Ludbrook A, et al. What works with men? A systematic review of health promoting interventions targeting men. *BMC Health Services Research*. 2008; 8:141doi:10.1186/1472-6963-8-141. Access at: <http://www.biomedcentral.com/1472-6963/8/141>



# 6

## DEVELOPING NEW RESOURCES

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# INTRODUCTION

**'It takes a lot of skill and effort to make information clear and accessible. The most important thing is to know from the very beginning what you want to do, why you want to do it, and how you're going to maintain it long-term. This is never as easy as it sounds.'**

**Colin Cosgrove, Editorial Manager, Macmillan Cancer Support**

## Issues to consider

Think carefully before you decide to produce your own information materials. Creating materials of a high standard requires specialised skills and a lot of time. Ask yourself if your centre has the resources to do this well and whether it would be a good use of time and money.

A wide range of high-quality cancer information materials is already available and it's best to use these whenever you can. (**See section 3** for more about assessing the quality of information materials). This is especially true now that the National cancer patient information pathways are reaching a well-developed stage (**see section 5**).

However, there may be rare occasions where it's appropriate to develop your own materials. One example might be a leaflet about accessing local services for people with cancer. This section of the toolkit explains how to go about the task.

Doing a good job will mean involving many people. For example, it's essential to involve service users. In addition, cancer networks keep track of local information resources and they should be consulted before you start. You will need an expert (or possibly several) to review the material for accuracy.

## Producing your own information materials

### Benefits

- Information can be tailored to local needs and services.
- Involving local users and the clinical team can enhance ownership.
- Volunteers may have experience in writing, design and production.

### Disadvantages

- You may end up duplicating information that already exists.
- Designing multimedia or web-based information requires specialist advice and guidance that may be expensive.
- Producing information materials may not be the best way to meet the needs you have identified.
- It's easy to make expensive mistakes, for example when briefing the printer and designer.
- It can take a long time to write and produce the information. On average, you need to allow nine months from the original idea to a finished resource.
- You will need to update the information regularly to ensure that it remains accurate and up-to-date.
- Printing can be expensive, especially when you are producing a small number of copies.
- Cancer information and support services-based within the NHS need to take account of the NHS identity guidelines – [nhsidentity.nhs.uk](https://www.nhs.uk/nhsidentity) The Department of Health has a toolkit called *Toolkit for producing patient information*. You can download it from [dh.gov.uk/publications](https://www.dh.gov.uk/publications)

If you are planning on producing an item with containing cancer information, contact Macmillan for guidance. Email [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)

# DEVELOPING A PRODUCTION PROTOCOL

The following is a general outline from which you can develop a production protocol for information materials. If there is a communications officer within your organisation, they will be able to advise you of any specific requirements in terms of process and house style.

## Stages in the production protocol

### 1. Identify the need

#### Who is it for? What is it about?

- Your material will have to meet the needs of your intended audience, and have clear aims.
- Work with users to develop an outline audience and subject area. Test it out with other users through questionnaires or focus groups.

#### Does this information already exist?

- Duplicating existing information wastes resources and could confuse service users with mixed messages.
- Consult the cancer network on information used/developed locally.
- Do a literature search and check *A directory of information materials for people affected by cancer* to see whether similar information already exists.
- Test any existing materials with focus groups to establish whether they would meet the identified need.
- If similar information materials exist that don't quite meet your needs, consider negotiating some changes with the producer of the existing resource before opting to produce new materials

### 2. Plan production and distribution

#### Editorial group

- You will need input from a variety of people to ensure high quality.
- Set up an editorial group, including users and clinical colleagues. It can also be helpful to involve a communications or information specialist.
- The editorial group will advise on developing content, production and distribution.

#### What is the best format?

- Providing accessible information helps to meet obligations under the Equality Act 2010 and is best practice.
- Check accessibility needs of the identified audience (including potential users).
- Consider whether you need to develop resources in alternative formats or languages.



### How will it be distributed?

- Be realistic about how many people you want to reach and why. Try to base this target on knowledge of your local population and their identified information needs. Money spent on wide distribution may be better spent on other services.
- Identify distribution processes and costs for a defined period of time.
- In addition to deciding how many copies you want, think about where they will be stored and how soon they will need to be updated.

### How is it going to be produced?

- Thinking this through at the beginning will help to keep your project on time and on budget, while ensuring good quality.
- Identify writers for different sections, an overall in-house writer or an external writer.
- Ask for a production quote to include additional costs such as printing more copies if you need them later, or website maintenance
- Seek advice on corporate identity and users' views on the use of illustrations.

### How much will it cost?

- Costs can quickly escalate so a realistic budget is very helpful.
- Identify costs and a budget to cover time, as well as any external fees such as writing costs, production, storage and distribution.

### How will the resource be evaluated, managed and reviewed?

- This is an essential step to ensure quality.
- The beginning of a project is the ideal time to build in evaluation. Decide how you will judge the success of the project, and how and when this will be measured later on.
- Agree a review period with the editorial group. It's good practice to update and revise clinical information at least every two years. Agree who will be responsible for maintaining the resource – who responds to comments or complaints, who will manage the review, etc.
- Ensure that copyright is assigned appropriately. This will make it much easier to revise the resource in the future. It will also establish who holds legal responsibility for the content. **See pages 93–95** for more information about copyright.

### Project brief

- You will get the best results from everyone in your team if they start out with a clear brief.
- Assemble all information gathered and agreed so far into a single document, which will serve as a key reference point to ensure the resource meets the needs initially identified.

## 3. First draft

### Write text

- Compile evidence base on issues to be covered – seek the advice of a library or information specialist on the most up-to-date evidence available.
- Agree on evidence sources to be used with editorial group and document reasons for selection of sources, to ensure balance and impartiality in the use of evidence.
- Draft text in style agreed by editorial group.

### **Circulate to editorial group**

- Circulate to editorial group, requesting comments on factual accuracy, consistency, clarity, sensitivity and use of language.
- Ensure that a representative mix of professional and user feedback is received, and document all feedback received.

## **4. Second draft**

### **Revise text**

- Take into account comments from editorial group. Where there are differences of opinion go back to the editorial group on the issue. If possible, identify where authority for resolution of differences sits (ie who has final say).

### **Test for quality and readability**

- Apply consumer health information quality tests and test for readability (**see section 3** of this guide). It may help to have someone impartial run these tests.

### **Consult on draft text**

- Consult users and clinical colleagues, requesting comments on whether it meets need(s) first identified (referring to the project brief), as well as factual accuracy, clarity, sensitivity and use of language.
- Circulate to reviewers or consider a focus group of users to ‘pre-test’ the resource.

## **5. Third draft**

### **Revise text**

- Take into account comments from all reviewers, including users. It’s vital to ensure that users have a meaningful level of influence in this process.
- Where there are irreconcilable differences on factual issues, state that there are different opinions and give references to published papers.

### **Initial design**

- Produce a design mock-up with the designer. This initial step is essential – having your designer do a complete draft can be an expensive mistake if your reviewers and editorial group don’t like it.

### **Circulate to reviewers and editorial group**

- Get the review group’s agreement on the design before you proceed.
- Once the resource has been laid out, request comments on both content and design. This should include whether the layout is readable, whether the content is easily navigable, and whether all accessibility requirements are being accounted for (or how these will be dealt with if the resource cannot meet all needs).

## 6. Final copy

### Revise copy

- Make any final changes to the text and design. Agree these with the editorial group.

### Proofreading

- Arrange proofreading of final copy. It's important to use an experienced proof reader who hasn't been involved in the production process, as they are more likely to spot any errors.

## 7. Print

### Production

- Send text to be printed, with agreed delivery arrangements. Ensure that publication date and planned review date are clearly visible.

### Checking print

- Check that no errors have occurred in the printing before arranging distribution.

## 8. Distribute

### Send materials out

- Monitor the distribution systems.

### Remove out-of-date resources

- If the information is an update of existing information, remove old copies to ensure that only the most up-to-date copy is in circulation.

## 9. Evaluate effectiveness

- Involve users in designing the evaluation and assessing the resource.
- Do an information audit to track its use.
- Compare its use with the initial need identified.

## 10. Review

### Updating

- Send out to users and clinical colleagues to review content after time agreed with the editorial group.
- Report to editorial group and assess whether a revised version is needed.
- Follow as many of the above steps as required to ensure the quality of the revision.
- You will also need planned, periodic 'spot checks' before the full review date, to make sure the resource has not become dangerously out of date.
- Plan for the additional possibility of an unscheduled review or update. This may be needed if users or experts point out errors or outdated information, after publication.

# DRAFTING THE CONTENT

**When you are writing content for cancer information materials, you need to take into account the design and presentation. This will have an impact on how you write the text for a leaflet or an audiovisual script.**

You may choose to work with a professional health writer with experience of producing booklets or other materials for users of health information. You will need to provide them with the sources for the content and a clear brief, including the purpose of the resource, writing style (including any established house style or identity requirements) and the anticipated format and layout, so that the writer can write sections of text to appropriate lengths.

## Assembling the evidence

Medical opinion varies, and assembling a balanced evidence base for information materials is difficult. Involving members of the editorial group in assessing the assembled evidence helps to ensure that it's balanced and that key papers or sources have not been overlooked.

## Clear purpose and structure

The topic and intended audience need to be clear in your opening text. If you are clear about the purpose of the resources, this will help you to structure the topic to meet the audience's needs.

Tables of contents, clear headings and boxes or bullet point summaries of each section help users to find their way around the text. The headings also help reviewers to assess whether the topic is handled in a way that addresses the purpose of the leaflet.

## Writing style

The Department of Health promotes materials that are 'clear, concise, relevant, accurate and in everyday language'.<sup>1</sup> An active personal voice, such as 'you can do X' rather than 'patients have the opportunity to do X', is easier to understand. Avoid jargon and abbreviations as far as possible. You may sometimes need to use a lay term followed by the medical term in brackets, if the medical term is one people are likely to hear used.

It's also a good idea to have a standard way of naming drugs. If you follow this format, you will cover all possibilities that the user may hear or read about elsewhere:

- At first mention, use the generic name, then list all brand names in brackets, eg trastuzumab (Herceptin).
- On following mentions, revert to the generic name only.



### Tips for accessible text style

- The style of the text has a significant impact on its readability.
- Use text that is not justified and is ranged to the left. This means text that is aligned on the left side of the column but is variable or ‘ragged’ on the right side of the column.
- Choose clean and modern fonts such as Arial or Tahoma.
- Choose a font size of at least 12 point, 16 for larger print formats.
- Online materials should give the option of viewing in a larger font size.
- Write in short sentences (15–20 words) and short paragraphs.
- Emphasise with bold rather than underlining words.
- Columns in tables should be separated by a ruled line.
- Include page numbers for ease of navigation.
- RNIB is a good source of information about accessibility for both print and digital resources. Visit [rnib.org.uk](http://rnib.org.uk)
- The Plain English Campaign has useful guides on clear writing (including some aspects of medical writing), design and layout, and useful tools to improve your text. Visit [plainenglish.co.uk](http://plainenglish.co.uk)

### Illustrations

Images are powerful so they must be chosen with care. Aim for positive portrayals and avoid condescending images. Select illustrations that provide a reflection of diversity that is appropriate to the topic and audience, including gender, age and ethnicity.

Illustrations, if used well, can provide useful shorthand for the contents of a leaflet for people with literacy problems. They can also help to explain the process of care by showing, for example, what a radiotherapy machine looks like. People with learning difficulties, however, often interpret illustrations literally, so a metaphorical image of a juggler would not be interpreted as shorthand for juggling options. Take care when using cartoons – conventions such as speech bubbles may be misunderstood and the meaning may be unclear or culturally specific.

If you are producing a Braille or large print version of the resource, you may need to produce a text description of the illustration for people who will not be able to see or understand the illustration itself.

Maps need to be well-designed with clear reference points, such as bus routes, road names and railway stations.

## Referencing sources/further reading

With increasing emphasis on evidence-based medicine and informed choice, it's important to include references, particularly on controversial issues, and to support information about risks and benefits of treatments.

You could consider using footnote reference numbers linked to a section at the end of the leaflet. This could be called 'If you would like more detailed information' and advise readers of how they can use the cancer information and support service to view copies of the papers.

You don't need to list every reference used in the resource itself, but users need to be aware that they can find more information if they need it. It's important to be able to identify the relevant evidence, and the reason for its selection, should there be any queries about the sources used.

## Details often overlooked

- Make sure the cover will stand out in display racks and the title is visible from a distance.
- Include a publication date (and a review date if one has been agreed).
- Include contact details for the cancer information and support service that developed the leaflet.
- Include details for ordering more copies.
- Name the author(s) and editorial group.
- Thank users for their involvement (not usually by name, unless they would like to be named). This also helps assessors of your information materials to see that there has been user involvement.
- Number the pages.
- Provide details of sources of support or further information for readers.
- If you are printing, make sure you use the right paper. For example, make sure it is thick enough so that text doesn't appear through the page, as this can make it difficult to read.

The Guild of Health Writers can put you in touch with a professional health writer if you are considering using one. Call **020 8941 2977** or email **admin@healthwriters.com**

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### Reference

<sup>1</sup> Department of Health. *Toolkit for producing patient information*. 2003. Available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4070141](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4070141)

# DEVELOPING A REVIEW PROCESS

**A thorough review process ensures that information materials meet the needs of your users.**

## Coordination of review process

If you have selected or developed the text, you should, ideally, have help from a colleague or volunteer to coordinate the review. You may be open to suggestions, but participants in the review process may not feel able to give their true opinions if they see you as having an interest or involvement in the material.

### Elements assessed in most review processes

- Format – appropriateness for the intended audience.
- Pitch and tone – check the content is informative without being distressing.
- Accuracy – factual accuracy of the text and any elements that are ambiguous or could be misinterpreted.
- Relevance – does it match the experiences of people affected by cancer?

## Selecting review methods

Before selecting a review method (see below), it's important to be clear about the outcome you expect from the review. Focus groups are useful for testing the concept of a proposed resource and whether it would meet a need. Groups are also a good mechanism to assess presentation, accessibility, the key messages being communicated and, most importantly, how presentation or content could be misunderstood. Paper reviews are better for assessing the detail of factual accuracy and readability of a resource. You may decide to use a range of review methods at different stages in the production.

The National Cancer Institute in the United States has developed clear guidance on research and review methods called *Making health communication programmes work*. It's available at [cancer.gov/cancertopics/cancerlibrary/pinkbook](https://cancer.gov/cancertopics/cancerlibrary/pinkbook)

## Conducting a paper review

This involves sending copies of the resource to reviewers, with a review form or guidance sheet indicating the aspects of the resource on which comments are needed. Reviewers should be given guidance on the review process, such as asking them to read through the text twice and address the specific questions on the review form on second reading.

### Elements to cover in review form sent out with copy of material to be reviewed

- Reviewers' interest(s) in cancer (a list of tick boxes can be helpful, remembering that many health professionals also have personal experience of cancer).
- Comments on the appropriateness of the resource (use of language, structure, format, use of images).
- Comments on factual accuracy (if it's a booklet or a script, you could ask respondents to scribble notes of inaccuracies on the text).
- Asking reviewers whether they would use the resource and whether they would recommend it to others can generate telling responses.

## Conducting a focus group review

As with a paper review, it's important to consider the issues that you want participants to comment on in advance of the meeting. In addition, the environment that the discussion takes place in should be discussed with members of the target audience, including use of translators, if appropriate, and refreshments. Choose an accessible venue and check whether any of your reviewers have any special needs.

## Reviewing materials in non-print formats

Materials in non-print formats tend to be much more expensive to produce than leaflets. Careful reviews of the concept are therefore particularly important.

### Reviewing draft materials in non-print formats

#### Audio resources

- Script and paper review
- Reading aloud and focus group or individual interviews
- Playing initial version of tape to individuals or focus groups  
(at this stage, changes are more costly, particularly in terms of time).

#### Video file or DVD resources

- 'Story board' (an outline of the action/interviews) and focus group
- Script and paper review
- Playing initial version of video file or DVD to a focus group or individuals  
(at this stage, major changes can be very expensive).

## Recruiting reviewers

It's important to allow plenty of time for recruiting reviewers. You need time to explain to each potential participant what the process would involve. If participants are clear about the level of commitment needed from the outset, they are more likely to take part fully.

## Taking comments into account

Reviewing information materials takes time. Having had support from your reviewers, it's important to be able to show them how their comments have been taken into account. If a difference of opinion emerges that cannot be resolved, it should be discussed with the editorial group. You may choose to mention in the text that the issue is one on which there is debate. If the difference of opinion is on a factual matter, provide references for each viewpoint.

# DIGITAL AND MULTIMEDIA RESOURCES

**If you are considering information materials in non-print formats, you need to consult widely to ensure that the format you have chosen is the best for the audience you are trying to reach. Digital resources, such as websites, may appear to be cheap, but the design costs can be high and the expectation that they will be updated creates pressure on services.**

## Issues to consider when developing multimedia resources

- How many people will be speaking on the recording? Will they be paid? If not, what expenses are you able to meet?
- Will all the participants be filmed/recorded in the same place on the same day? The more days and locations needed, the more expensive the production.
- Will people be using a script or their own words? A script may sound less natural, but you will need a good interviewer and editor to ensure that key information is covered if people don't have a script or key points on which to speak.
- What permissions should you get? You will need signed releases and conditions of use, especially when patients are involved.

## Producing audio materials

Materials in audio formats such as CDs and MP3s are potentially very flexible. Participants can describe services as though they are in a treatment centre, even though they are in a recording studio. Fully scripted audio materials tend to work better than scripted visual materials, because the script itself doesn't have to be learned or hidden from viewers. The reading of the script shouldn't be rushed – aim for about 120 words a minute.

If you are producing audio versions of material that was originally produced in print, you shouldn't simply record the printed document without some planning. Think about how you can create the same effect that design features such as images or emboldened text would have made on the printed version.

Professional audio materials often include a piece of introductory music, some sound effects, a presenter and a variety of tones. Make sure you gain permission from anyone you've recorded before producing audio materials. You may want to commission a specialist in audio production to help you develop the resource.<sup>1</sup>

## Accessibility issues for audio resources

Do members of the community you are trying to reach play CDs or listen to audio files on an MP3 player or computer? It's worth remembering that access to such technology can be a barrier for some older people and those on lower incomes.

Older people may prefer audiocassette recordings but these are relatively expensive to make and their use is dwindling. They are also more difficult to navigate than CDs.

Information is easier to follow if it's well-structured. This is particularly important with an audio resource, as there are no visual clues. Even if there isn't one in the original document, make a contents list and communicate this to the listener so they know how to access specific sections of information if they need to.<sup>1</sup>

## Producing video files and DVDs

With the widespread use of digital filming, the flexibility of filmed resources has greatly increased. Digital clips can be included on DVDs or websites. YouTube is the most popular video sharing website. It can be used to upload your video resource and make it accessible to a large online audience.

If you want to keep and use the footage that is edited out of the final product, ensure that this is covered both in your contract with the production company and the agreement you make with people who are filmed. You should also get written permission from any participants that have been filmed.

How long do you intend the resource to use the resource for? Generic discussion of living with cancer is likely to remain current for longer than specific treatment details.

Where will people be watching it? Is this a resource that people will be watching in the privacy of their homes, or will it be available in an information centre or clinic?

When checking the contract, make sure that you will see rough cuts and agree the final version before it's copied. Costs for duplication vary and some producers will only work on jobs when they are guaranteed all duplication rights, so check the terms and rates.

## Producing digital resources

Digital resources can hold information in a wide range of formats. Before you begin thinking about the inclusion of music, film clips and animation, it's important to ensure that the resource is well-structured. Websites, CDs and DVDs can contain vast quantities of information. If people are going to find their way through the information, the structure needs to be very clear (see site map example opposite).

## Classic website and CD-Rom structure



When developing the digital resource, you will need help from the editorial group. Ask them to check that all the links work and that it is easy to find information and 'backtrack' through the site.

The European Union E-Commerce Directive 2002 requires websites to include:

- full contact details
- the logo and name of producing organisation on every page
- a declaration of whether 'cookies' are used to collect data
- a declaration of how any personal data collected will be used.

There are key differences between expectations of a website and a CD or DVD. Frequency of updates, opportunities to offer feedback and accessibility all need to be taken into account. The development plan for the website needs to include allocation of resources for regular updating of the site.

Guidance on ensuring that resources are accessible to people with visual impairment is available from RNIB ([rnib.org.uk](http://rnib.org.uk)) on their 'Good design' pages.

To ensure that online resources are accessible to people with disabilities, follow the Web Accessibility Initiative guidelines at [w3.org/WAI/](http://w3.org/WAI/)

**Selecting, managing and developing information materials can be complex. Support is available from the Macmillan Information and Support Programme Manager on 020 7091 2122 or from Macmillan's Cancer Information Development team on 020 7840 4682.**

# CHECKLIST AND FURTHER READING

## Checklist

Develop a production protocol

Identify need

Confirm format

Draft the content

Set up review processes

Review and revise the content

Publish/print copy

Disseminate publication

Evaluate effectiveness

Review

## Further reading

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# APPENDIX 1: MACMILLAN QUALITY IN INFORMATION AND SUPPORT SERVICES

**Macmillan Quality in Information and Support Services (MQulSS) has 12 quality areas:**

- **planning**
- **governance**
- **leadership and management**
- **user-centred service**
- **managing people**
- **learning and development**
- **managing money**
- **managing resources**
- **communication and promotion**
- **working with others**
- **monitoring and evaluation**
- **results (which looks at the outcomes of the other quality areas).**

Each quality area has a number of quality indicators – statements of good practice in this specific area. The quality areas also have five ‘levels’ against which the service can self-assess. The idea is that the service looks at the level it’s currently reaching, and if it’s not already at the top level, the description of the levels above provides guidance on what they need to do to improve practice.

**Quality area** – eg ‘managing resources’ with a high-level aim (criterion).

**Indicators** that describe good practice.

Each indicator describes **5 levels** – excellent (5) to nothing in place (1).

The following information lists the ‘criteria’: the high-level aims of each quality area.

## Quality area 1: planning

### Criterion

The service has a clear overall purpose and has sustainable plans for what it will achieve in the current year, based on the needs and expectations of users, the partner organisation and Macmillan. Major risks are identified and managed. Progress against plans is regularly monitored.

### Indicators

- 1** The service’s specific aims and intended outcomes are based on the needs of users, including minority groups and professional users.
- 2** The annual plan for the current year is informed by consultation with users and knowledge of other relevant services.
- 3** Plans for the current year include realistic and achievable targets for the most important outputs for the year.
- 4** Planning for new services is based on the needs of users.
- 5** Plans for the current year make clear reference to NHS and Macmillan policy, and to the needs of funders.
- 6** Major risks are identified, including risks to the safety of people and plans address ways to manage these.
- 7** The service regularly reviews its progress against its plans.

## Quality area 2: governance

### Criterion

The roles and responsibilities of the service, Macmillan and the partner organisation are agreed, understood and documented. The service works effectively with Macmillan and the host organisation, and meets their requirements.

### Indicators

- 1** The respective roles and responsibilities of the service, Macmillan and the partner organisation are clearly defined and documented. Staff and volunteers understand these roles.
- 2** Working practices, procedures and protocols are agreed between the service, Macmillan and the partner organisation. These are clearly documented.
- 3** The service produces an annual report, which is made available to stakeholders.

## Quality area 3: leadership and management

### Criterion

The service has leadership that develops staff motivation and initiative. Good internal communication increases commitment to the service's plans. The service manager oversees the service's development, the quality of its activities and its progress against agreed outcomes.

### Indicators

- 1** The service manager leads by example, providing clear direction, coaching and support to achieve service outcomes.
- 2** The service manager encourages continuous learning and improvement, and leads the development of a high-quality service.
- 3** The service manager makes sure that staff and volunteers know how to get things done to meet legal and service requirements and achieve outcomes for users.
- 4** The service manager promotes and fosters effective internal communication. This encourages and facilitates staff and volunteer initiative.

## Quality area 4: user-centred service

### Criterion

The service identifies its users, and places them at the centre of its design, delivery and review of services and activities. The service avoids unfair discrimination and makes its services accessible. The service is focused on achieving better outcomes for users and represents their interests.

### Indicators

- 1 People who may need the service are clearly defined, and population groups targeted to prevent unfair discrimination or exclusion from services.
- 2 Services and activities are based on the identified needs of users, including minorities and people with disabilities.
- 3 The service plans, promotes and delivers its services and activities so that it is fully inclusive to its users.
- 4 The organisation works closely with individual users to identify their needs, agree desired outcomes and review how needs are being met.
- 5 Users are given detailed information about relevant national and local services, support groups and activities, and are encouraged to make appropriate choices.
- 6 User feedback is encouraged, recorded and analysed. Complaints are dealt with openly and promptly.

## Quality area 5: managing people

### Criterion

Staff and volunteers have the appropriate skills, knowledge and experience to provide a safe, reliable service and information is shared in the team. They know who they are accountable to, understand their role and are supported to carry it out in order to achieve the aims of the service.

### Indicators

- 1 The service recruits enough people with the right knowledge, skills and experience to achieve its aims.
- 2 The service meets legal responsibilities and equal opportunities requirements in its recruitment and employment practices.
- 3 All staff and volunteers have documented roles, responsibilities and accountabilities, and understand what they have to do.
- 4 New people are told about the organisation and its work and how their role relates to other roles, and are given enough information to be safe, efficient and effective.
- 5 Staff and volunteers get enough individual support and supervision to carry out their work effectively.
- 6 Relevant news and information is shared, and meetings are held with staff and volunteers to discuss the service's activities.



## Quality area 6: learning and development

### Criterion

Training and other opportunities for learning are seen as an essential part of individual and service development. The service learns from its own and others' knowledge, expertise and experience, and uses this learning to achieve continuous improvement. Learning and development are resourced, encouraged and monitored.

### Indicators

- 1** Staff/volunteers are aware of and share information about training and other learning opportunities offered by the host organisation and Macmillan.
- 2** Staff/volunteers have records of their development needs for the current year. Attendance at learning events is recorded and learning events are evaluated.
- 3** Team meetings, briefings and contact with other organisations enable people to develop their knowledge and learn from others.
- 4** Staff and volunteers receive training in how to provide information in a supportive manner.
- 5** Staff and volunteers receive training to understand the information needs of people affected by cancer, and to develop knowledge and skills to answer enquiries safely within the limitations of their role.

## Quality area 7: managing money

### Criterion

The service meets all legal requirements in relation to money, and spends its money on agreed purposes. There are basic financial procedures in place.

*This indicator will only be answered partially by some services, depending on their financial responsibilities.*

### Indicators

- 1** The service meets the requirements of the law, regulatory standards and its Macmillan service agreement in managing and accounting for money.
- 2** A realistic and affordable annual budget is agreed and adjustments made in the light of expenditure information and forecasts.
- 3** There are written procedures for authorising payments, signing cheques, handling donations, petty cash and staff/volunteer expenses.

## Quality area 8: managing resources

### Criterion

There are enough resources to manage and deliver planned information services and other activities safely, efficiently and effectively. The service uses a variety of methods to provide accessible, high-quality information, including generating and dispensing information prescriptions. The service manages resources in a way that helps protect the environment.

### Indicators

- 1 There are enough resources to deliver the services and activities planned for the current year.
- 2 Premises are secure, welcoming and accessible, and meet the requirements of equality legislation.
- 3 Basic records on supply and delivery are kept.
- 4 Resources and working practices meet all health and safety and other relevant legal requirements.
- 5 The service has management policies and systems which ensure that relevant, good-quality printed information for users on cancer and related topics is updated, always available, and can be located easily.
- 6 The service has policies and systems in place to ensure that information supplied to users is reliable and safe, and is managed effectively and in line with legislation. Information management policies are in line with relevant Macmillan and NHS guidance.
- 7 The service has enough suitable ICT equipment to enable access for users and staff to electronic information systems, including information prescriptions. Staff/volunteers are given appropriate training to support users' information needs using electronic systems.
- 8 Personal and sensitive information is held securely and managed in accordance with data protection and other legislation and guidance, ensuring confidentiality where necessary.
- 9 The organisation considers its environmental responsibilities and takes steps to save energy, reduce waste, and to re-use or recycle materials.

## Quality area 9: communication and promotion

### Criterion

The service is clear about what it wants to communicate and to whom, and communicates effectively in accessible formats with users and stakeholders. It takes steps to promote its work to users, professionals and related organisations, and represents the needs of its users.

### Indicators

- 1** The service is clear about the key messages it wants to communicate to users and other external stakeholders. It identifies itself as a Macmillan service.
- 2** The service maintains an up-to-date contact list of external stakeholders.
- 3** Promotional material about the service is displayed in a variety of places. The promotional material contains essential information about the service and activities available, including how to contact the organisation.
- 4** Nominated individuals within the service are authorised to write and speak publicly on its behalf.
- 5** The service advocates the needs of user groups to relevant agencies and individuals.

## Quality area 10: working with others

### Criterion

The service builds relations and networks with other relevant organisations, working with them effectively to support its specific aims and to benefit users. It creates opportunities to work with others to improve efficiency and effectiveness, influence change and achieve better outcomes for users.

### Indicators

- 1** The service identifies key organisations that it needs to work for a range of purposes and maintains up-to-date information about the services and activities of other relevant organisations.
- 2** There are clear procedures for when and how to signpost or refer users to other appropriate organisations or to another part of the host organisation or Macmillan. All signposting and referrals are recorded.
- 3** Staff and volunteers from the service participate in relevant networks and forums.
- 4** When working with others, there is a clear understanding about who will do what, and how any expenditure will be managed.

## Quality area 11: monitoring and evaluation

### Criterion

The service routinely tracks its activities and outcomes. It assesses how well it is doing and uses this information for decision-making and planning and to report to Macmillan and the partner organisation.

### Indicators

- 1 Decisions about what to monitor and evaluate are based on an understanding of what the service, Macmillan and the host organisation need to know.
- 2 There is a monitoring and evaluation system that records information about users, and monitors outputs and outcomes.
- 3 The service records and reports on feedback from users, including complaints and suggestions.
- 4 The service builds its monitoring and evaluation skills and systems by accessing external information, training and other support.
- 5 Monitoring information is regularly collated and reviewed, feeding back into daily practice and informing management decisions.
- 6 Monitoring and evaluation findings are reported to users, Macmillan and the host organisation, to meet their information requirements and are used for making quality improvements and planning.

## Quality area 12: results

### Criterion

Users are satisfied with the service and receive identifiable benefits. The service has competent staff and volunteers, and the working environment is good. Planned services are carried out and quality improvements made. There is evidence of contributions to the wider community.

This criterion encompasses user results, people results, organisational results and community results.

### This QA looks at the outcomes of the other 11 QAs:

#### QA12a – user results

- 1 The service is easily identifiable and contactable.
- 2 The user group is consistent with the intended target group.
- 3 User feedback shows that users are satisfied with the service and that their information and support needs and preferences have been met.
- 4 Planned outcomes are achieved.

#### QA12b – people results

- 1 Stated competency requirements for staff and volunteer roles are met.
- 2 Staff and volunteers feel they are treated fairly.
- 3 There are indications that staff morale is good.
- 4 Health and safety audits demonstrate that legal requirements have been met.



**QA12c – organisational results**

- 1** The service is resourced to carry out its plans.
- 2** The service’s use of resources matches available resources.
- 3** Most services, activities and their outputs are delivered as planned.
- 4** The service is known and respected by other relevant organisations.
- 5** There are identifiable improvements related to quality action plans.
- 6** Services and activities are enhanced by learning obtained from monitoring and evaluation information.

**QA12d – community results**

- 1** Staff and volunteer employment demonstrate a contribution to the wider community.
- 2** Trend information shows continued improvements in savings in the use of environmental resources.

# DISCLAIMER

We make every effort to ensure that the information we provide is accurate and up-to-date. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information such as information on websites to which we link. We feature real life stories in all of our articles. Some photographs are of models.

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**Cancer is the toughest fight most of us will ever face. If you or someone you know has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.**

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.

**Questions about living with cancer?  
Call the Macmillan Support Line free on  
0808 808 00 00 (Mon–Fri 9am–8pm)**

**Alternatively, visit [macmillan.org.uk](http://macmillan.org.uk)  
Hard of hearing? Use textphone  
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