

Judge: Web Sites for Health. Support Group Guidelines

To assist support groups to produce good quality Web sites.

Based on the views of health consumers and support groups.

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SUPPORT GROUP GUIDELINES

These guidelines aim to help support groups produce good quality Web sites. They are arranged in four main sections.

- How to produce good quality information
- How to design good quality Web sites
- How to market Web sites
- How to help consumers use health information from the Internet

1. HOW TO PRODUCE GOOD QUALITY INFORMATION

This section describes the principles to follow to help ensure that the information you provide on your Web site is of good quality.

The contents of this section are listed below.

- Trust and reputation
- Details of the organisation
- Purpose of the organisation
- Associated organisations
- Funding sources
- The way the information is written
- Non-English language material
- Descriptions of conditions and treatments
- Medical research
- Personal experiences
- Communication
- Links to other sites
- Data protection
- Copyright
- Terms and conditions
- Disclaimers
- Kitemarks
- Advertising
- Interactive facilities - e-mail lists, bulletin boards, chat rooms
- Other quality guidelines

1.1 Trust and reputation

In normal life we make judgements based on our trust in an organisation or an individual. This is true of Web sites too.

Organisations need to be clear and honest about who they are, what their purpose is and who funds and sponsors them.

Give details of any standards or principles that you follow when you produce your site, for example:

- the Health On the Net Foundation Code of Conduct (HONcode) (<http://www.hon.ch/HONcode/Conduct.html>).

1.2 Details of the organisation

The name of your organisation should be clear and obvious on every page of the site.

Provide full details about your organisation.

This information is usually put in sections called "About us" and "Contact us". It includes, where applicable:

- Contact details:
 - (a) name of organisation;
 - (b) postal address;
 - (c) telephone number;
 - (d) fax number;
 - (e) e-mail address.

- Location:
 - (a) map;
 - (b) details of how to reach your organisation by car and public transport;
 - (c) opening hours.

- Charitable status:
 - (a) registered charity number.

- List of staff:
 - (a) name;
 - (b) job title;
 - (c) responsibilities;
 - (d) photo;
 - (e) individual contact details.

- List of other people involved, for example Management Committee, Medical Advisory Panel, Editorial Board:
 - (a) names;
 - (b) role in your organisation;
 - (c) role outside your organisation, for example job title and employing organisation, or consumer representative;
 - (d) photo;
 - (e) individual contact details.

When you include personal details on your Web site, for example names and photos, you must abide by the Data Protection Act (see section 1.13).

1.3 Purpose of the organisation

Describe your organisation, purpose and aims:

- type of organisation, such as support group;
- charitable status, for example registered charity number;
- why and when your group was started;
- purpose and aims;
- strategy, activities;
- annual reports.

Describe the purpose of your Web site:

- its aims;
- its intended audience;
- how it was developed, particularly if health consumers were involved and how.

1.4 Associated organisations

Give details of any organisation or group you are associated or affiliated with.

This helps people decide on the reliability of your information, for example if you work with a medical organisation.

This suggests any potential bias in the information you provide, for example if you are associated with a pharmaceutical or medical product company.

1.5 Funding sources

The sources of funding for the organisation and site should be clear. Information should be given about any potential bias or conflicts of interest, such as your sponsors and the adverts you take.

- Finances:
 - (a) sources of funding;
 - (b) accounts;
 - (c) registered charity number with link to the Charity Commission's Web site (<http://www.charity-commission.gov.uk/>) .
- Donations and items for sale:
 - (a) place in a clearly marked separate section, for example 'How you can help', 'Publications', 'Shop';
 - (b) clearly describe the price and method of payment.
- Possible bias or conflicts of interest:
 - (a) give names of sponsors, both individual and corporate;
 - (b) people might be cautious of sites sponsored by e.g. pharmaceutical or medical product companies;
 - (c) if you do not accept sponsorship you should say so;
 - (d) the types of adverts you take could indicate possible bias.

1.6 The way the information is written

Writing for the Web is different to writing for a printed document. People scan Web pages quickly to obtain information, rather than settling down for a long read.

Information should be kept up to date:

- include date written and date updated;
- for information that does not change rapidly, include a regular review date, for example yearly;
- the home page must contain a last modified / updated date.

Information should be balanced:

- discussing different sides of an issue;
- not sensational;
- with no extreme statements or extravagant claims.

Information should be simply and correctly written:

- simple and easy to understand;
- no medical jargon;
- with explanations of medical terms, by providing a glossary, and a link to an on-line medical dictionary, e.g. The Free Dictionary, produced by Farlex (<http://medical-dictionary.thefreedictionary.com/>);
- with correct grammar and spelling.

Information should be kept short:

- keeping the amount of text on a Web page short;
- using short, simple sentences;
- using bullet points to break up the text, and show key points;

If you want to make larger documents available, e.g. newsletters, leaflets, annual reports, put them in PDF or word-processed format with a link to the document from the Web site.

- Check the final version of the document with an anti-virus programme. There are many products available, for example:
 - (a) McAfee VirusScan (<http://uk.mcafee.com/>);
 - (b) Norton AntiVirus (<http://www.symantec.com/>).
 - (c) free virus checkers - look for recommendations from users and experts, e.g. The Guardian newspaper's Ask Jack Blog (<http://www.guardian.co.uk/technology/askjack+security>)
- Tell the user the format of the document and how large it is.
- Include a summary of the content of the document on the Web site.
- For PDF files, give a link to the ADOBE site for users to obtain the free reader software (<http://www.adobe.co.uk/products/acrobat/readstep2.html>).

Some organisations give guidance on how to produce readable, accessible information, for example:

- Plain English Campaign (<http://www.plainenglish.co.uk/>);
- National Information Forum (<http://www.nif.org.uk/>).

1.7 Non-English language material

If your site is targeting groups with a first-language other than English, it might be appropriate for information to be provided in those languages as well.

Translating information into other languages is not simple.

- There are Web sites offering automatic, computer translation, but:
 - (a) they only translate small amounts of text;
 - (b) they only cover a few languages, usually the common European languages.
- It needs a human translator.
- Proper translation is more than just changing words, for example:
 - (a) a literal translation of the English topic may not exist in some languages;
 - (b) the translator needs to understand what the topic means to the people speaking the other language.
- The Department of Health recommends that 'back' translation is carried out on all translated materials, which means:
 - (a) a different translator translates the final draft back into English to check that the meaning is correct.

You must consider your ability to set up and manage foreign language content and whether you have the funding to do so.

1.8 Descriptions of conditions and treatments

There are two levels to ensuring the quality of this medical information.

First level

The use of quality principles will indicate to people that the information is likely to be reliable. Include these details with each piece of medical information:

- the name of the author, with the reasons why people should trust what they have written, for example their job title, place of work, formal qualifications;

- any potential conflicts of interest, for example the researcher is funded by a pharmaceutical company;
- the date the information was written, with an update or review date:
 - (a) some information, like the description of a disease, does not change very much. However it should be reviewed on a regular basis, for example yearly, to check that it is still correct;
- the sources of the information the author used to write their section, for example:
 - (a) references to the literature;
 - (b) links to other Web sites, including the date they were accessed to obtain information;
 - (c) statements about their knowledge and experience;
- contact details so people can check up on the information and query it;
- links to related resources so people can read other opinions and look at other research.

Include a page on the site where you describe any quality checks or editorial processes that medical information goes through before it is placed on your site.

Second level

This is a detailed assessment of the correctness of the information. It requires a health professional or a lay-expert.

A lay-expert is a member of the public, often a patient or a carer, who has spent a lot of time reading and learning about a specific medical condition. They can know as much about this small area of medicine as some health professionals.

- Set up an Advisory Medical Panel.
- Ask medical experts to write material for your site.
- Develop lay-expertise.

1.9 Medical research

The medical research literature is very complex. You need specialised knowledge of the subject, the scientific methods used and the terminology to be able to understand it fully.

The nature and strength of science is in debate. Scientists test and challenge each others' work until they reach agreement. This approach is very powerful

at building up knowledge and understanding. However, it is not helpful or comfortable for the health consumer looking for certainty, for example:

- a piece of work can be out of date, overtaken by further research;
- experts can have different opinions about the research;
- professional advice can vary between different countries;
- some researchers' ideas can be at odds with the usual opinion.

To produce good quality coverage of medical research:

- set up an Advisory Medical Panel, who can advise if a piece of research is relevant and up to date;
- ask medical experts to write about current and new research for your site;
- develop lay-expertise:
(a) a lay-expert is a member of the public, often a patient or a carer, who has spent a lot of time reading and learning about a specific medical condition. They can know as much about this small area of medicine as some health professionals.

If you highlight current or new research on your site or in your newsletter:

- give a lay person's summary;
- give the full reference to the original article.

There are a number of useful sources to the medical research literature. Here are some examples.

- NHS Evidence Health Information Resources (<http://www.library.nhs.uk/>)
NHS Evidence Health Information Resources website (formerly the National Library for Health - NLH) produced by the NHS. It contains good quality information that provides the evidence for health care. Though aimed at the health professional, most of the site is freely available to the public too. A number of the databases are also free to the public, such as the 'Cochrane Library'.
- MEDLINEplus (<http://medlineplus.gov/>)
MEDLINEplus is produced by the US government. It is a gateway to health information for the health consumer. It provides information on conditions, a medical encyclopaedia and medical dictionaries. For every condition covered, you can click on a link to MEDLINE for a pre-set search of recent research articles. MEDLINE is the top database to the international medical research literature.
- MEDLINE (<http://www.pubmed.gov>)
MEDLINE is produced by the US government. It is the top database to the international medical research literature. It is made available free on the Web.

You will have to learn how to use and search the database. Detailed help and a tutorial are available from the MEDLINE site.

1.10 Personal experiences

Personal experiences are important sources of help and information.

- Clearly mark personal experiences as personal experiences.
- Try to include 'success' stories and look at the pros and cons of a condition.
- Ensure that no details could identify the individual concerned **or**:
- Obtain written permission from the individual to make their personal information publicly available.
- Ensure that they do not contain inaccurate statements about medical facts and treatments.
- Challenging service provision and professional practice with the aim of improving them is an important aspect. However the identification of individual people and organisations could cause problems. You may need to take legal advice.

1.11 Communication

Communication is a particular strength of support group sites.

Methods to make contact with the support group, for discussion and feedback, should be built in, for example:

- contact phone number or helpline;
- an e-mail address:
 - (a) send an auto-reply acknowledging receipt of the e-mail, and saying if and when they might expect a reply;
- a postal address;
- an electronic form:
 - (a) send an auto-reply acknowledging receipt of the form, and saying if and when they might expect a reply.

Inform people of any limits placed on this communication, for example:

- Are phone helplines only staffed for fixed time periods?
 - (a) Can people leave messages on an answerphone?
 - (b) Will they receive a reply?
 - (c) How many days before they can expect an answer?

- Are e-mail support services only staffed for fixed time periods?
 - (a) Will they receive a reply?
 - (b) How many days before they can expect an answer?
- If you cannot provide individual responses make this clear.

People also need to be able to contact the Web site manager, to report technical problems and to provide comments about the site.

1.12 Links to other sites

Links to other Web sites can be useful sources of information. However you must first decide if your organisation wishes to make any links at all.

Reasons for linking

- The whole purpose and benefit of the Internet is linking to other sites.
- Links give your users access to further information, for example other organisations and resources in the same field or information on related topics which you do not cover.
- You can guide your users to good quality sites.
- Links allow people to check what you've said.

Reasons against linking

- You need to check the trustworthiness of the organisation, the quality of their Web site, the reliability of their content.
- Sites change. You need the people and time to check that links still work and that the sites' quality has stayed the time.
- You cannot check the sites that the sites you link to link to in their turn, and so on.
- You could be open to legal challenge if someone was damaged from information obtained from a site you linked to.
- It could be safer and easier not to link.

You need to take responsibility for any external links you make.

- Establish policies and procedures and publish these on your site.
- Establish principles for judging the quality of Web sites and publish these on your site:

- (a) use these 'Judge: Web site for health. Support group guidelines';
 - (b) use other quality guidelines (see section 1.20).
- Check out the organisation and assess their Web site and its content using these quality principles.
 - Linking can raise copyright issues (see section 1.14):
 - (a) check if they have given global permission on their site to allow people to make links, particularly deep linking;
 - (b) if not, ask permission of the organisation to link to their site.
 - Put a disclaimer about links on your site.
 - Include the Web address as part of the link text, for example 'http://www.google.co.uk' not just 'Google'.
 - (a) When a person prints a page of your site the link will still make sense.
 - Make it clear to a user that they are linking to another site, for example:
 - (a) a message saying they are leaving the current site;
 - (b) a new browser window opening when they click on the link.
 - Make sure that the links still exist, by checking them on a regular basis.

If you have linked to another organisation's Web site, it does not automatically mean they will place a link on their site to your site. If you want them to do so, write to them with details of your site, its aims and URL, and ask if they will link to you in return.

1.13 Data protection

The Data Protection Act covers the use of personal data, which is anything that could identify a living person. Any organisation collecting personal data through their Web site (or by other means) must obey this law. You must:

- explain that you are obtaining personal data and what you are using it for:
 - (a) if the data is 'sensitive', for example information about ethnicity, health or disabilities, you must ask for permission first;
- only use this data for the reason you give;
- only ask for data that is relevant and necessary;
- ensure the data is correct and up-to-date:
 - (a) people can ask to see their data and correct it;
- only keep data as long as it is necessary:
 - (a) when it is no longer needed, or is out of date, it should be deleted;

- abide by people's rights;
- keep data confidential and secure;
- not transfer data outside the EU.

The Information Commissioner's Office (<http://www.ico.gov.uk/>) enforces the Data Protection Act.

This site provides a number of guides for further information, (http://www.ico.gov.uk/tools_and_resources/document_library/data_protection.aspx).

1.14 Copyright

Web sites and their contents are protected by copyright law. They are protected in the same way as printed material. This happens automatically.

Your copyright

- People can copy information from your site for the purposes of non-commercial research and personal study.
 - They must acknowledge you and your site as the source.
 - They cannot reproduce your information unless they have your permission.
- (a) You may wish in your 'Terms and conditions of use' to specify what copyright permissions, if any, you will give to your users.

Other people's copyright

- You may not use any copyrighted information on your site unless you have received permission from the copyright owner.
- Ask for their permission in writing .

Linking to other people's Web sites from your Web site

- Links to the home page of another Web site is acceptable. However, it is good practice to ask the organisation's permission, in writing.
- 'Deep linking', where you make a link directly to a page or resource inside a site and bypass the home page, could be interpreted as breaking that site's copyright. It could therefore be essential to ask the organisation's permission to do this.

- Check the terms and conditions of a site to see if they have given people permission to link to their site, particularly to deep link.
- If your site uses frames and a user clicks on a link, the text from that other site is automatically 'included' in your Web site. This 'framing' is clearly breaking copyright. You must always ask an organisation's permission to do this.
(a) However use of frames is also not recommended from a design viewpoint.
- It is good practice to indicate that the user is leaving your site when they click on an external link, or to make an external link open up in a new browser window. This makes it clear to a user that the linked site is nothing to do with your site.

Guidelines for UK public sector websites

(<http://www.coi.gov.uk/guidance.php?page=188>), "Section on Legal issues", discusses copyright and gives suggestions for terms and conditions that can be placed on Web sites.

Creative Commons (<http://creativecommons.org/>), is a nonprofit organisation that provides free tools for setting up copyright licenses that can be placed on Web sites.

1.15 Terms and conditions

Explain the terms and conditions under which you produce your site.

Privacy

You are bound by the Data Protection Act (see section 1.13). You must give information about:

- whether you use cookies or not;
- whether you ask for personal information or not, or just accept personal information volunteered by the user, for example if they send you an e-mail;
- what you do with this personal information.

Copyright

You have copyright to the information on your site (see section 1.14). However you may wish to give users various permissions, for example:

- to reproduce your information as long as this is done accurately, the source is identified and your copyright is acknowledged;

- to link directly to individual pages or resources within your site ('deep linking').

Accuracy

Explain your policy and procedures for ensuring that the information on your site is correct, for example Expert Medical Panel, Editorial Board.

Links to other sites

Explain your policy for making links, and how you judge the quality of these sites (see section 1.12).

1.16 Disclaimers

Include disclaimers so people understand the limits to what your site can do. You might need to get legal advice on this.

Medical information

- Medical information on the Internet is not intended to replace consultation with a person's own doctor.

Guarantees and responsibility for harm

- You cannot guarantee the accuracy and currency of the information you provide.
- You cannot be held responsible for any problems users of your site might encounter or harm they might be caused.

Availability

- You cannot guarantee your site will always be available.

Links to other sites

- You do not endorse the organisation or its site.
- You do not guarantee the quality of their information.
- You do not guarantee that the site will be available.

Virus protection

- This disclaimer is only necessary if you provide information in formats other than html, for example PDF or word-processed files, for people to download.

- People should always use an anti-virus programme on any material downloaded from a Web site.
- You cannot accept responsibility if people are affected by a virus from using material available through your Web site.

Guidelines for UK public sector websites

(<http://www.coi.gov.uk/guidance.php?page=188>), "Section on Legal issues", discusses disclaimers and gives suggestions for terms and conditions that can be placed on Web sites.

1.17 Kitemarks

Obtaining endorsement from other organisations, demonstrated by the presence of their logo, or kitemark, on your site, can be helpful, but it is not a requirement. The absence of a kitemark is not necessarily a sign of poor quality. Only a minority of sites apply for them.

Kitemarks can mean many different things. The principles used to judge sites will vary between the endorsing organisations. The presence of such an award cannot be taken as a guarantee of the accuracy of the health information on the site.

Here are some examples of common kitemarks.

- Health On the Net Foundation Code of Conduct (HONcode) (<http://www.hon.ch/HONcode/Conduct.html>)
HON is a not-for-profit International Swiss Organisation. It has produced a set of eight ethical principles, the HONcode, that Web site producers should abide by. However it does not rate the quality of the information provided by a Web site. Approved organisations can place an active logo on their site. When a person clicks on this logo they will see a page on the HON site with details of the current status of the organisation.
- Department of Health, Information Standard (<http://www.dh.gov.uk/en/Healthcare/PatientChoice/BetterInformationChoicesHealth/Informationstandard/index.htm>)
This scheme, about to be launched, will 'kitemark' health information providers.
- Bobby (<http://www.mardiros.net/bobby-accessibility-tool.html>)
Bobby is a software tool that Web site producers can use to check that their site is accessible to people with disabilities.
- The British Medical Association (BMA) Patient Information Award (http://www.bma.org.uk/whats_on/offers_and_competitions/LIBBMAPatientInformationAward.jsp)

The BMA Patient Information Award is part of the BMA Medical Book Competition. A separate category for consumer Web sites has existed from 2000.

- Plain English Campaign Internet Crystal Mark (<http://www.plainenglish.co.uk/crystal-mark/internet-crystal-mark.html>).

1.18 Advertising

Users could judge you by the amount and type of advertising you place on your site. The type of advertising could also suggest to users a possible bias in the information you provide, for example if you advertised a pharmaceutical product or a health care product or service.

If you take advertising:

- make sure the company and product are not incompatible with your organisation's purpose;
- keep it discrete;
- make it obvious that adverts are adverts.

1.19 Interactive facilities

You may have interactive facilities on your Web site, for example social networking sites, chat rooms, e-mail lists, bulletin boards. These also need quality checking.

Consider carefully if you want to offer interactive facilities.

- They can be very time consuming to manage.
- It can be very difficult to control what information people give and the correctness of that information.
- You could be liable for any comments posted.

Quality controls on interactive facilities include:

- Experienced members, who respond when incorrect information is broadcast.
- The use of Netiquette - rules of polite, supportive behaviour on the Internet. Produce a set of rules about acceptable behaviour that users must sign up to before participating. These rules should cover aspects such as:
 - (a) only making supportive not critical comments;
 - (b) staying on topic;
 - (c) no insults, threats, swearing, abuse, obscene comments, and so on;

- (d) no discriminatory comments, for example on race, gender, age, sexuality, religion, nationality;
- (e) no illegal comments, for example libel;
- (f) no spamming;
- (g) no advertising or endorsement of products or services;
- (h) no impersonation.

- Moderators who help the discussions stay supportive and within the rules. Moderators are people who control what happens in the facility.
 - (a) They register new members, tell them about the acceptable behaviour rules, prevent, delete or modify inappropriate messages, and ban offenders from the group.
 - (b) Moderators can either deal with messages and offenders after the inappropriate message has been posted, or check all messages before hand. Checking beforehand can be very time consuming.
- Setting up closed facilities, where registration is required

1.20 Other quality guidelines

Here are some examples of other quality guidelines. There are many more.

- Intute Collection Development Framework and Policy
(http://www.intute.ac.uk/supportdocs/IntuteCDFPJuly2009_final.pdf)
The health information gateway, Intute: Medicine including dentistry (<http://www.intute.ac.uk/healthandlifesciences/medicine/>) is part of Intute (produced by the higher education sector). These guidelines explain how Intute evaluates Internet resources for inclusion in their gateway.
- Health On the Net Foundation Code of Conduct (HONcode)
(<http://www.hon.ch/HONcode/Conduct.html>)
HON is a not-for-profit International Swiss Organisation. It has produced a set of eight ethical principles, the HONcode, that Web site producers should abide by. However it does not rate the quality of the information provided by a Web site.
- QUICK - The Quality Information Checklist
(<http://www.avon.k12.ct.us/enrichment/Enrich/quickgr4-0.htm>)
QUICK is aimed at children to help them evaluate the information they find on the Internet.

2. HOW TO DESIGN GOOD QUALITY WEB SITES

This section describes the principles to follow to help ensure that your Web site is well designed.

The contents of this section are listed below.

- Practicalities
- Principles of good design
- Accessibility
- Accessibility - fonts, colours and graphics
- Accessibility - use of technology
- Usability
- Appearance
- Testing and evaluation
- Maintenance and development

2.1 Practicalities

Straightforward Web sites can be produced by individuals with a reasonable experience of using computers.

Software tools make the job simple. If you want to look at the basics of writing html there are plenty of books and free Web resources that offer guidance. Two simple introductions to writing html are:

- Dave Raggett, Getting started with HTML, revised 24 May 2005, (<http://www.w3.org/MarkUp/Guide/>);
- HTML Source (<http://www.yourhtmlsource.com/>).

Software products that you can buy which enable you to produce Web sites easily include:

- Adobe Dreamweaver (<http://www.adobe.com/products/dreamweaver/>);
- Microsoft Expression (<http://www.microsoft.com/uk/expression/default.aspx>).

You could find a taster session or short course on Web site design at local organisations like the WEA (Workers' Educational Association), further education colleges or universities.

However the main 'cost' of a Web site is the time required to set it up and then to maintain it on a regular basis. An out of date Web site is worse than no Web site at all.

Make sure you retain control of your Web site. An enthusiastic group member may offer to produce your site. But what will happen if their enthusiasm dies down or they leave the group or the area?

- The group should subscribe to the domain name, ISP, and so on, not an individual.
- Keep details of how to access the server where your Web site is held, particularly any ids and passwords.
- Keep copies of the html files that make up your Web site.

It might be more effective to hire someone to set up and maintain your site on your behalf.

- Many small companies offer this service. Search for them on the Internet, or check out other organisations' Web sites to see who maintains them.
- Make sure you get several quotes and properly written contracts, just as you would with any other product or service.
- It is possible that you can obtain a grant to help with the costs.
- Check the terms and conditions of the contract carefully to ensure that you hold the copyright to the site and all its content and design features.
- Once again, make sure you retain control of the site. If you decide not to renew the contract you must be able to continue with the site and maintain and update it.

Another option is to see if your local college or university is looking for suggestions for student projects or organisations offering work placements. Once again make sure you retain control of the site.

2.2 Principles of good design

Good Web site design covers the following issues:

- accessibility;
- usability;
- appearance.

Plan out your design on paper first.

- Think about what information you want to include in your site. Section 2 in these guidelines on 'How to produce good quality information' will provide suggestions.

- How will the different sections of information be logically connected to each other? This helps you to think how the site's navigation will be organised.
- Look at the following pages in this section 2 'How to design good quality Web sites'.
 - (a) Some of the pages give quite detailed advice for people with more computer expertise who are producing their own sites.
 - (b) Also look at the other guides to Web design listed below for further details.
 - (c) If someone else is producing the Web site for you, these pages will help you discuss the design requirements with them.
- A Web site can be built up gradually, as long as you leave places in your design to build in future sections

When planning the design of your site, think about your users and make it simple, obvious, and helpful.

Look at other Web sites. What do you think is good about them? What is unhelpful or poor?

There are many sites that provide advice on good Web design, for example:

- NHS Brand Guidelines (<http://www.nhsidentity.nhs.uk/>)
- Royal National Institute for the Blind (RNIB) Web access centre (http://www.rnib.org.uk/professionals/webaccessibility/Pages/web_accessibility.aspx). RNIB is the leading UK charity offering practical support and advice to anyone with a sight problem;
- Plain English tips for clear websites (<http://www.plainenglish.co.uk/files/websitesguide.pdf>);
- Guidelines for UK public sector websites (<http://www.coi.gov.uk/guidance.php?page=188>);
- Web Accessibility Initiative (<http://www.w3.org/WAI/>);
- Freepint e-mail newsletter and Web site, including tips for Web site producers (<http://www.freepint.com>).

2.3 Accessibility

The aim is to make your site easily accessible to all, and to reduce any barriers to its use by:

- people with disabilities, such as sight, hearing, or physical problems, learning difficulties;
- older people, with sight, hearing, physical or cognitive problems;
- inexperienced Internet users;
- people using different types of technology;
- people using older technology;
- non-English speakers, if you are targeting such groups.

Sites designed for these user groups will be accessible by all.

The Disability Discrimination Act requires organisations to make their facilities and services accessible to disabled people. Look at the Equality and Human Rights Commission site for further information (<http://www.equalityhumanrights.com/>).

The following sections discuss:

- Accessibility - fonts, colours and graphics (section 2.4)
- Accessibility - use of technology (section 2.5)

2.4 Accessibility - fonts, colours, graphics and audio

Careful use of fonts, colours and graphics is very important, particularly to make your site accessible to people with visual problems.

The Royal National Institute for the Blind (RNIB) has a Web access centre (http://www.rnib.org.uk/professionals/webaccessibility/Pages/web_accessibility.aspx).

Use fonts (size and colour) that can be easily read, and / or changed by the user as required.

- Do not specify particular fonts or typefaces or, if you do, provide options for alternatives to be used.
- If you specify fonts, only use a few different fonts - common ones, sans serif, standard (medium) size.
- Ensure the site will work at different screen resolutions.
- Don't use light text on dark backgrounds - it causes printing problems.
- Use single, solid background colours - avoid background images, patterns or textures.
- Underlined text means a hypertext link - if you want to emphasise a piece of normal text use bold.

- Sections of text completely in upper case or italics can be difficult to read.
- Use only a few colours that go well together.
- Avoid colour combinations that cause problems for people with colour-blindness (red / green, yellow / blue) or dyslexia.
- Avoid colour combinations where the contrast between the colours is low - look at the colours in grey scale to see how they will appear.

Navigation around the site is vital.

- Don't use graphics or active content for navigation.
- Avoid drop-down menus and pop-up windows. If you use them, provide an alternative.
- Use the same methods of navigation throughout your site

Be sparing in your use of graphics and only use them if you have a good reason:

- If you use graphics to convey important content always provide a text alternative.
- Use alt-tags with all images or graphics:
 - (a) Alt-tags (alternative text attribute (ALT text)) are shown in place of images in text or text reader browsers. They also appear in some browsers when the cursor rests on an icon or image on the screen;
 - (b) make sure they briefly but clearly describe what the image or icon is.
- If you provide moving graphics keep them in a separate section of the site, clearly labelled as such.

You should also consider the needs of people with hearing problems if you include audio material on your site. Provide transcripts or captions.

2.5 Accessibility - use of technology

People use MACs as well as PCs, have different versions of software not just the most recent, use different Web browsers, and different versions of those browsers not just the most recent.

- Examples of different Web browsers include:
 - (a) Microsoft Internet Explorer (<http://www.microsoft.com/windows/internet-explorer/default.aspx>);
 - (b) AOL Netscape (<http://www.netscape.com>);
 - (c) Mozilla Firefox (<http://www.mozilla.org>);

(d) Google Chrome (<http://www.google.com/chrome>).

- Use open Internet standards, not proprietary formats.
- If possible, test your site with different browsers to see that it will work and how it looks.

Complex technical design and the use of additional software are barriers to people with older technology or inexperienced in using computers and the Internet. They can also be expensive in connect time.

- Avoid using software that requires plug-ins like Flash.
- Avoid using frames, or offer a frame-free version.
- Be careful how you use tables. There are lots of accessibility issues associated with these. For more information check the World Wide Web Consortium's (W3C) Web site (<http://www.w3.org/WAI/>).
- Make sure that your site downloads quickly, especially the home page;
(a) as a general rule of thumb, some text must be readable within 10 seconds.
- Avoid large graphics. They can take a long time to download.
- If you have large documents as PDF or word-processed files:
(a) say how large they are so people can decide whether to download them;
(b) provide a text summary;
(c) for PDF files, give a link to the ADOBE site for users to obtain the free reader software (<http://www.adobe.co.uk/products/acrobat/readstep2.html>).

Only use a technique in your design if you have a good reason to do so. Unnecessary design elements are annoying and frustrating to users.

- Avoid splash pages; a home page where the user has to click on an "enter" button to access the site or wait a short while for entry.
- Avoid the use of gimmicks, for example blinking text, animations, spinning logos, 3D graphics, music, clip art.
- Be sparing of technology, for example Javascript and Flash, and only use it if it has a real purpose.

2.6 Usability

The aim is to make your site easy to use and to enable people to find the information they want quickly.

Arrange the content into a clear, logical structure

- Group similar information together into sections with appropriate connections within and between sections.
- However don't create too many levels. Users don't like to make a lot of clicks before they get to the content.

Make the navigation between sections of the site clear and logical

- Navigation links are usually positioned in menus at the side (particularly the left hand side) and/or the top of the screen.
- Firstly there is a global set of links, for example to your site's home page, the main sections of the site, your parent organisation's home page.
- Secondly there is a specific set of links that relate to connections within a given section of the site. These links will obviously vary between sections.
- Depending on the size of the site and of the pages, there could be a set of links (Top, Bottom, Previous, Next) on individual pages.
- In addition to these navigation links there will be other links within the content of the pages. These direct users to relevant pages both within and outside the site.
- Put navigation links near the top of the page so users don't have to wait for the whole page to download before moving on.
- Give indications of where the user is within the site.
- Provide facilities so people can browse, for example a site map and / or an A/Z index.
- Consider providing a site search facility. A search facility is complementary to the browse facilities, not a replacement.

Keep individual pages short

- If you have a lot of text that you want to present, break it up into a series of linked, short pages.
- Alternatively, consider providing a brief summary and making the full version available as a downloadable word processed or PDF file.

2.7 Appearance

An accessible, usable site can also be attractive and pleasing to the user.

Design classics are often simple, for example the Google Web site (<http://www.google.co.uk>).

Attractiveness is personal and subjective. Look at other sites for ideas and suggestions.

2.8 Testing and evaluation

All sites need to be tested.

Testing ensures that the site really is accessible and usable. It also shows up flaws in the content.

Test it with your users.

- When you are designing your site, test it with a sample of your users.
- When you make major changes, remember to test these with your users too.
- Provide a facility on your site for user feedback so they can give you their views on the site and tell you about anything that is causing problems.

There are also resources that you can use to check the accessibility and usability of your Web site, for example:

- Bobby (<http://www.mardiros.net/bobby-accessibility-tool.html>);
- Validator - a free service that checks that html documents conform to W3C (World Wide Web Consortium) recommendations and other standards (<http://validator.w3.org>);
- W3C (World Wide Web Consortium) provides a list of such tools (<http://www.w3.org/WAI/ER/tools/>).

While testing your site don't make it publicly available.

- You can create the site on your own computer and look at the html files in a browser, without having to place it on a server.
- If it is placed on a server people are unlikely to find it unless you have marketed it first.
- If you have a current site, don't make the links active which connect the new sections to the public parts of your site.

2.9 Maintenance and development

All sites need to be maintained regularly and to be changed and developed over time.

Maintenance can be a significant demand on people's time. You need to consider how you will sustain your Web site.

- Good planning at the design stage can reduce the burden of maintenance, for example, by limiting the number of external links that would require regular checking.
- At the design stage try to anticipate your future needs and build in locations in your structure for growth and change. This will reduce major changes to the site.
- Avoid links to the parts of your site that are 'under construction'. Only link to parts that are active.

3. HOW TO MARKET WEB SITES

This section describes how to market your Web site so you can reach your intended audience.

The contents of this section are listed below.

- Web site address
- Keywords
- Search engine listings
- Linking to your site
- Traditional methods

3.1 Web site address

Select a Web site address (a domain name) for your site that is simple and meaningful.

The URL (uniform resource locator) is the standard way of specifying the location of a Web page, its Web address.

The 'domain name' of a Web site is the first part of the Web address, between `http://` and the first `/`, for example:

- `http://www.cafamily.org.uk/;`
- `http://omni.ac.uk/.`

This 'domain name' is the unique name which identifies that organisation on the Internet. Its different sections are as follows:

- `http` means hypertext transfer protocol;
- punctuation, which separates the various components of the URL;
- `www` means world wide web. This is usually present but not always;
- first part, such as 'cafamily' or 'omni', is the part of the domain name that an organisation can choose. It cannot be currently in use by anyone else;
- codes representing the type of organisation and its country of origin.

Common organisational codes (top level domains, TLDs) include:

`.com` (for commercial organisations);
`.edu` (for educational organisations);
`.gov` (for governments);
`.org` (for organisations, usually non-commercial).

Country codes (country level domains) for example:

no code (for the USA);
.au (for Australia);
.int (for international);
.uk (for the UK).

Second level codes (domains, SLDs) for example:

.ac.uk (for educational organisations in the UK);
.co.uk (for commercial organisations in the UK);
.org.uk (for organisations, usually non-commercial, in the UK).

Most support groups would use .org.uk or .org.

You have to register your domain name with an accredited organisation. Only organisations accredited by ICANN (Internet Corporation for Assigned Names and Numbers) can register domain names. A list of these accredited organisations is available as a link from the ICANN FAQs Web page (<http://www.icann.org/en/faq/>).

Nominet UK (<http://www.nominet.org.uk>) is the Registry for .uk Internet Domain Names. Nominet manages the second level domains within the UK.

You will have to pay to register so shop around for the cheapest price. If you can afford it, consider buying your name with a range of organisational codes (for example .org, .org.uk, .com, .co.uk) as people often make errors when typing in a Web address. These 'ghost' sites can be set to automatically link to your site. You have exclusive right to your domain name for the registration period.

You will have invested a lot of time and effort in marketing your site so **remember to renew** your registration. Check the price and conditions for renewal before you register.

However buying your domain name does not include Web space and this will have to be obtained from another source, for example any ISP (Internet Service Provider), or companies who register domain names and sell other services.

3.2 Keywords

To improve the chances of a search engine finding your site in response to a person's search, you need to include appropriate keywords.

Place important keywords in the text at the top of your pages. When writing your content always bear in mind the need for these keywords.

Include keywords and other descriptive information in the beginning section of your html code. This type of information is called meta data.

- Meta data is information that defines and describes data.
- It appears at the beginning of the html code in the 'Head' section and is invisible to the user.
- To see the meta data used by a site, click on 'view' and 'source' in the browser menu.

You should include this minimal amount of meta data for your site. Meta data should be used for every page:

Title of the Web page

This appears in the title bar of the browser, the search engine listing, and the description when someone bookmarks the site. The keywords it contains are used by the search engine to find the site.

- `<TITLE> xxx </TITLE>`.
- About 15-20 words.
- Use the main keywords that describe your site, for example "Judge: web sites for health - support group guidelines - how to market Web sites".

Description of the site or page

This will be used by some search engines as the summary in search results.

- `<META NAME="description" CONTENT="xxx">`.
- 200-250 characters.
- Make it readable and informative.

Keywords

Some search engines use these to find the site.

- `<META NAME="keywords" CONTENT="xxx">`.
- Up to 1,000 characters.
- Include common spelling errors and different versions of words.

For further information see How To Use HTML Meta Tags, Search Engine Watch, 5 Mar 2007, (<http://searchenginewatch.com/2167931>).

3.3 Search engine listings

Another way of improving the chances of a search engine finding your site in response to a person's search is to submit (register) your site with a range of search engines, directories (collections of Internet sites grouped by subject) or gateways (free searchable catalogues of health Internet sites).

- Look for menu items like 'Submit your URL', 'Add your URL', 'Suggest a site', 'Submit a site'.
- Check out what details they require first and get these all prepared before you make an on-line submission.
- You may have to pay.
- Check that you are included / listed. It can take some time (weeks) before you are actually included.
- However there is no guarantee they will use your site. If they do not, re-apply after a few months.
- Resubmit after major changes to your site

Here are some examples of search engines, directories and gateways.

- Google (<http://www.google.co.uk>).
- AllTheWeb (<http://www.alltheweb.com>).
- Yahoo (<http://www.yahoo.com>).
- MedHunt (<http://www.hon.ch/>).
- NHS Choices (<http://www.nhs.uk/>)
- NHS Direct (<http://www.nhsdirect.nhs.uk>).
- Contact a Family (<http://www.cafamily.org.uk>).
- Patient UK (<http://www.patient.co.uk>).
- Intute: Medicine including dentistry (<http://www.intute.ac.uk/healthandlifesciences/medicine/>).
- NHS Evidence Health Information Resources (<http://www.library.nhs.uk/>).

For further information see Search Engine Watch. (SEM Search Engine Marketing) Basics. (<http://searchenginewatch.com/WEBmasTERs>).

3.4 Linking to your site

Getting other sites to link to your site is important for a number of reasons.

- It is part of the process of helping users move around good quality information on the Web.
- It promotes networking between related organisations.
- Search engines use linkages between sites as a way of recognising sites that they will want to include in their listings.

Ask other organisations if they will link to your site:

- However check first that they haven't already linked to you.
- When you contact them you will need to send your URL, site title and a brief description of your site and its aims.
- You may need to offer reciprocal linking so check out the quality of their site first to see if you would want to link to them
- If you change the address of your site, make sure you redirect from **all** your old pages, not just the old home page.

3.5 Traditional methods

Print methods are still effective marketing tools, even for Web sites.

- Put your Web address (and e-mail address if you want public contact through that route) on all your publications and products, including:
 - (a) letterheads, business cards, compliment slips;
 - (b) newsletters, leaflets;
 - (c) anything written by or about you, such as articles, adverts;
 - (d) automatic e-mail 'signatures'. However include the 'signature' as simple text within the e-mail, not as an attachment or image;
 - (f) promotional products, such as cards, tee shirts, mouse mats;
 - (g) answerphone, or line holding, messages.
- Officially launch your Web site. Send out press releases.

All these methods produce 'word of mouth' advertising which, in the long run, is the most effective.

4. HOW TO HELP CONSUMERS USE HEALTH INFORMATION

This section discusses how you can help people to search for, judge and use health information on the Internet.

The contents of this section are listed below.

- Promoting the value of information
- Using gateways - searchable catalogues of health Internet sites
- Using search engines
- Search tips and confidence building - learning how to search
- Judging the quality of information
- Managing information in partnership with health professionals

4.1 Promoting the value of information

Process of looking for information

The process of looking for information is important. It helps many people adjust to their condition.

There are stages to a condition. Different types of information may be needed at these different stages.

- Before a diagnosis:
 - (a) to work out what the problem is.
- Just after a diagnosis:
 - (a) to find out why it has happened;
 - (b) to find anything that might help.
- Later on in the condition:
 - (a) to focus on the things that work for you;
 - (b) to find more detailed information;
 - (c) to read the medical research literature.

Support groups as sources of information

At all these stages, it can be very helpful for a person to make contact with a support group for their particular condition, and to talk to someone in the group. So helping people to find the Web sites of national or local support groups is very important.

Provide local organisations with your contact details, including your site URL, for example:

- GP practices, hospitals and special clinics;
- Patient Advice and Liaison Service (PALS) in Trusts;

- public libraries;
- social services;
- local authorities;
- education authorities.

Promote the value and importance of giving people contact details of support groups.

4.2 Using gateways

Health gateways provide free access to a catalogue of health and medical Internet sites. You can look for information under subject sections, or search the gateway using keywords.

- Advise health consumers to use gateways first, rather than to go straight to a search engine.
- Provide links to gateways on your site.

There are a number of gateways that would be useful. Here are some examples.

- NHS Choices (<http://www.nhs.uk/>)
NHS Choices is produced by the NHS. It provides information about NHS services, healthy living and treatments and conditions.
- NHS Direct (<http://www.nhsdirect.nhs.uk>)
NHS Direct is produced by the NHS. It provides high quality health information and advice. You can also make an online enquiry, or telephone a 24 hour nurse advice and information helpline.
- Contact a Family (<http://www.cafamily.org.uk>)
Contact a Family produces a directory of conditions affecting adults and children. The directory gives a medical description of the condition, followed by details of related support groups. There is also a helpline service. Contact a Family is a UK charity which helps families who care for children with any disability or special need. They are a main source of information about rare disorders and are able to assist affected adults as well as children.
- Patient UK (<http://www.patient.co.uk>)
Patient UK is a directory to health Web sites in the UK. It contains information about conditions, support groups, books and journals, and locations of GP practices and hospitals. Patient information leaflets are also available. It is a free site edited by two GPs.
- Intute: Medicine including dentistry
(<http://www.intute.ac.uk/healthandlifesciences/medicine/>)

This is "a free online service providing you with access to the very best web resources for education and research, evaluated and selected by a network of subject specialists. This service was formerly known as OMNI."

- NHS Evidence Health Information Resources (<http://www.library.nhs.uk/>)
NHS Evidence Health Information Resources website (formerly the National Library for Health - NLH) is produced by the NHS. It contains good quality information that provides the evidence for health care. Though aimed at the health professional, most of the site is freely available to the public too.

- MEDLINEplus (<http://medlineplus.gov>)
MEDLINEplus is produced by the US government. It provides information on conditions, a medical encyclopaedia and medical dictionaries. For every condition covered, you can click on a link to MEDLINE for a pre-set search of recent research articles. MEDLINE is the top database to the international medical research literature.

- MEDLINE (<http://www.pubmed.gov>)
MEDLINE is produced by the US government. It is the top database to the international medical research literature. It is available free on the Web.

4.3 Using search engines

Advise people to use search engines if they cannot find what they want from the gateways.

Provide links to one or two search engines from your site.

Here are some examples of search engines.

- Google (<http://www.google.co.uk>).
- AllTheWeb (<http://www.alltheweb.com>).
- Yahoo (<http://www.yahoo.com>)
Yahoo also includes a directory where human editors have organised Web sites under categories, including 'Health'.
- MedHunt (<http://www.hon.ch/>)
MedHunt is a medical search engine provided by the Health On the Net Foundation (HON), a not-for-profit International Swiss Organisation.

If you want to find out about individual search engines and what they do go to Phil Bradley's Finding information: search engines (<http://www.philb.com/whichengine.htm>).

4.4 Search tips and confidence building

Search tips

Give a few hints about how to use search engines more effectively.

- Unless your search is very simple, always use the 'advanced search' option provided by the search engine (normally a link near to the search box on the home page). 'Advanced search' allows you to do things like:
 - (a) find results with all of the words you type in your query. This makes it much more likely to find relevant sites and cuts down on the number of results;
 - (b) find results with the exact phrase, by putting the words in quote marks "...". This is very useful when looking for names of diseases, organisations, people;
 - (c) choose the language, for example English.
- The Help pages will give you details about how to use the search engine and how to search more efficiently.
- If you use only one or two search engines then time spent reading their Help pages will be well worth it.
- When using other search tools like gateways and directories look at their Help pages too.
- A summary leaflet of the Judge: web sites for health "How to search" section of the consumer guidelines is available. You can make copies to handout to other people.

Confidence building

A person's confidence in searching the Internet for information can be increased if they learn more about how to search.

- Suggest that people take taster sessions or short courses at local organisations like the public library, the WEA (Workers' Educational Association), further education colleges or universities. There may be a small fee for courses.
- Recommend the local public library as a place where they can get free access to the Internet

There are Web sites that provide free online tutorials so you could think of placing links to these on your site. Here are some examples.

- The Online Netskills Interactive Course - TONIC
(<http://www.netskills.ac.uk/onlinecourses/tonic>)

TONIC: is free but users have to register so their progress can be tracked and they can be given feedback. It is produced by the higher education sector in the UK.

- Intute: Virtual Training Suite (<http://www.vts.intute.ac.uk/>)
These online tutorials are designed to help people improve their Internet information literacy and IT skills. No registration is required, and you can use them at your own pace with no monitoring. They are produced by the higher education sector in the UK.

4.5 Judging the quality of information

Give people guidance on how to judge the quality of health information they find on the Internet.

Provide a copy of the Judge: Web sites for health, consumer guidelines.

Provide links to other quality guidelines. Here are some examples.

- Intute Collection Development Framework and Policy
(http://www.intute.ac.uk/supportdocs/IntuteCDFPJuly2009_final.pdf)
The health information gateway, Intute: Medicine including dentistry (<http://www.intute.ac.uk/healthandlifesciences/medicine/>) is part of Intute (produced by the higher education sector). These guidelines explain how Intute evaluates Internet resources for inclusion in their gateway.
- The Health On the Net Foundation Code of Conduct (HONcode)
(<http://www.hon.ch/HONcode/Conduct.html>)
HON is a not-for-profit International Swiss Organisation. It has produced a set of eight ethical principles, the HONcode, that Web site producers should abide by. However it does not rate the quality of the information provided by a Web site.

4.6 Managing information in partnership with health professionals

Give tips on how health consumers could best ask their doctor about information they have found on the Internet, for example a piece of medical research, a particular therapy or drug.

Suggest they talk it over with a support group first. This could answer many of their questions. However you must make it clear that support groups cannot replace consultation with a doctor.

Advise them to make best use of the short consultation time they will have with a very busy doctor by:

- selecting one piece of high quality information, from a professional medical source:

- (a) written by a doctor or medical researcher;
 - (b) with the author's name and details;
 - (c) the date, and details of the source;
 - (d) the Web address;
- taking this to the consultation:
 - (a) or sending the information in advance so the doctor has time to read it.

ABOUT JUDGE

The Judge project has developed guidelines for judging the quality of health information Web sites.

Two sets of guidelines have been produced:

- to help health consumers make informed choices about Web sites:
- Judge: Web Sites for Health. Consumer Guidelines;
- to assist support groups to produce good quality Web sites:
- Judge: Web Sites For Health. Support Group Guidelines.

The Judge project was developed in partnership between:

Contact a Family (<http://www.cafamily.org.uk>) the national charity dedicated to helping families who care for children with any disability or special need;

Information Management Research Institute (IMRI), School of Informatics, Northumbria University (now Information Management Innovation Research Group (<http://northumbria.ac.uk/sd/academic/ceis/re/isrc/>), School of Computing, Engineering and Information Sciences).

The project was supported by the PPP Foundation (now the Health Foundation).

The Centre for Health Information Quality (now closed) developed this Web site in collaboration with IMRI.

A Steering Group advised the project. Its members were from:

- The Alzheimer's Society (<http://www.alzheimers.org.uk>);
- The Centre for Health information Quality (CHIQ) (now closed);
- The National electronic Library for Health (NeLH) (now NHS Evidence Health Information Resources (<http://www.library.nhs.uk/>);
- The National Information Forum (<http://www.nif.org.uk>);
- Organising Medical Networked Information (OMNI) (now Intute: Medicine including dentistry (<http://www.intute.ac.uk/healthandlifesciences/medicine/>);
- Patient UK (<http://www.patient.org.uk>).

The project has resulted in a number of published journal articles:

- Childs S (2005). Judging the quality of Internet-based health information. *Performance Measurement and Metrics*, 6(2):80-96
- Childs S (2004). Developing health web site quality assessment guidelines for the voluntary sector: Outcomes from the Judge project. *Health Information and Libraries Journal*, 21(Suppl 2):14-26

Disclaimer

The information in these guidelines was written by an information professional, based on the views of health consumers and support groups. It does not contain medical information. If you have a medical question please contact your doctor.

Although obtaining information from the Internet can be very helpful, it is not a replacement for consulting your own doctor, but additional to the information and advice they provide.

We have taken care in the production of these guidelines. However we cannot accept responsibility for any errors or omissions. We cannot be responsible for any loss, damage or expense that might be caused by any action, or lack of action, that a person might take as a result of reading these guidelines. Responsibility for such actions, or lack of actions, remains with the reader concerned.

We have provided the Web addresses of external Web sites but we have no responsibility for these sites. We cannot guarantee the quality of their information, or if they are still accessible. We do not endorse any product or service.

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Feedback

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This resource does not provide medical information and we cannot answer medical questions. If you have a medical question please contact your doctor.