The Patient Information Forum

The Patient Information Forum is the UK organisation for people who work in consumer health information. It was founded in 1997 from a desire to see an improvement in the quality and availability of health information for patients and the public. High quality information was starting to be recognised as a key element in the successful management of any health condition, particularly long-term medical conditions, and the prevention of ill health. Since then the issue of quality consumer health information has continued to grow in importance among policy makers, health professionals and the public themselves. In response PiF has also grown from a small voluntary network to a large membership organisation. In essence PiF can now be seen as the professional body for people who work in the field of consumer health information.

PiF members come from across the UK and from a diverse range of sectors including the NHS, commercial, voluntary and academia. Roles are varied but focus on understanding and improving communication with patients and the public about their health. The PiF network provides members with opportunities to:

- **Be part of a strong collective, independent voice**
  PiF speaks up for the people and organisations that produce and provide information - raising important issues with Government, national and local policy makers.

- **Promote and support excellence**
  PiF provides training, education and guidance. We develop and promote quality standards and provide consumer health information staff with the tools they need to do their jobs better.

- **Make information better**
  Members of the network share their expertise and experience and support each other - we provide opportunities to discuss the key issues and find solutions to problems.

For more information about the Patient Information Forum and membership please go to [www.pifonline.org.uk](http://www.pifonline.org.uk)
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### Acknowledgements

PiF would like to thank all of the PiF members who contributed case studies, perspectives and references for this guide. In particular we would also like to thank Danielle Swain at Picker Institute Europe, Terry Cawley at Doncaster PCT and Dr Jo Ellins at the University of Birmingham for their input.

**Cost:** Free to download from the PiF website for PiF members (www.pifonline.org.uk). £20 for a printed copy.

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This guide was developed by PiF following a workshop which took place on 30 June 2009. Both the workshop and production of this guide were supported by a grant from Merck Sharp & Dohme Limited. The views expressed in this publication are those of the authors and contributors and are not necessarily those of the sponsors, Merck Sharp & Dohme Limited.
Before the Internet, medical knowledge was safely locked away in the minds of doctors and medical libraries, most of which did not give access to patients and the public. Public libraries had some knowledge available but usually very limited, for example limited to the Medical Directory, the names and qualifications of doctors, and a small number of “home doctor” books written specifically for the laity.

The Internet has blown away the locked doors of libraries as effectively as Semtex but, as is common when dealing with a complex problem, every solution creates further problems. The problem of lack of access to any information was replaced by the problem of being completely overwhelmed with information. Furthermore, just as in the early days of the printing press, people believed that if it was on the web it must be true, a belief which fortunately did not last very long but which was a problem in the early days of the web. Now, however, the problem is appraising the quality of the information and health knowledge provided, because knowledge has quality as well as quantity.

The simplest approach is to tell people that the principle is caveat lector - let the reader beware; be critical of everything but although there is a morally pure line, it is not terribly useful because there is still a choice. Steps have been taken to improve information from trusted sources, for example through NHS Choices, or the development of decision aids or the development of the Information Standard, but in the end the individual has to make a decision based not only on the strength of evidence but also on their own values.

Mitch Karpor* said that trying to get knowledge off the Internet was like drinking from a burst fire hydrant; the image is tremendous. This guide will help information producers to assess the quality of the information they develop and provide - and ultimately this helps the most important person in the healthcare system, the member of the public, sometimes called the patient, to find what they need and decide if it is fit for purpose.

Sir Muir Gray, CBE
Consultant in Public Health
Director, NHS National Knowledge Service
• High quality information is a vital part of any individual’s engagement with healthcare and health services - it can lead to constructive dialogue with health professionals, encourage self care and promote effective self management, and give individuals real control over their health.

• There is no one set of quality standards or guidelines accepted and recognised for use across the UK, for either individual resources or the processes used to develop them. Neither is there just one tool that can be used to appraise all information materials.

• There are many benefits and challenges of producing and using high quality information for both users and information producers. However, appraising quality is not always straightforward and there are a number of challenges to be faced.

• There are quality markers for consumer health information on which consensus has been broadly reached - these include accuracy, reliability, relevance, accessibility, balance and comprehensiveness. There are many others, some of which relate to specific formats.

• Arguably the biggest impact on consumer health information, and on quality, in the last decade has come from the growth of the Internet. There have been widespread concerns about the quality of online information, however there is little evidence that it is harmful.

• When appraising the quality of either your own work, or that of another organisation there are two routes open to you - the formal and the informal. Formal methods are usually applying criteria developed by an accrediting organisation, informal methods rely on self-appraisal.

• Quality marks are a visible way of demonstrating that an organisation has reached a certain standard. However, this relies on the quality scheme being robust, respected and consistently applied, and most importantly it relies on the end user recognising and understanding the quality mark and using it to inform their decisions.

• If an organisation has an excellent process for developing information it does not necessarily mean that they will produce high quality materials.

• The Information Standard certification scheme in England has helped information producers to develop better and more streamlined processes for developing their information. However, the impact on resources, and thus on patients and the public of the scheme has yet to be assessed.

• The NHS in all four countries of the UK has quality standards for the production and provision of consumer health information.

• Tools for rating quality come in a number of formats - codes of conduct, self applied quality labels, guidelines for users, filtering tools and quality marks awarded by third parties. All of these can be useful but ultimately they rely on consumers to use them appropriately.

• As a rule, readability formulae can be useful tools, but should only be used as a guide, because they do have limitations. Text may score well when put through a readability tool, but it can still be meaningless, inaccurate or misleading.
• The person making the final judgement on quality is the end user - therefore they have to be equipped to make a judgement. Either patients and the public need to have critical appraisal skills to help them decide, or they need to recognise a quality mark and know what it stands for.

• Users of health information should perhaps be the ones leading the way in the search for quality. Users could judge quality based on their experiences of using it. Collective ratings from a large number of individuals could help to identify the good and worthwhile information, from the not so good or so useful.
Audit our information service
- Go to the part of Chapter One titled ‘Appraising quality,’ to see what general options are open to you.
- Read the ‘Background’ part of Chapter Two for general information about quality processes, and chapter three for appraisal tools.
- Read the case study on information audit on page 46.

Develop quality standards for our organisation
- Read the part of Chapter Three about ‘Guidelines for developing high quality information.’
- Read the part of Chapter One titled ‘What is quality in the context of consumer health information?’
- Read the ‘Background’ part of Chapter Two.

Appraise a piece of information for readability
- Go to the part of Chapter Three that looks at readability tools - read the case study about using the Flesch readability score and the instructions for how to use the Fry Formula, Gunning Fog Index and SMOG.
- Make sure that you also read the information about the down-side of readability tools.

Find out more about the Information Standard
- Go to Chapter Two and read about the Information Standard, including personal perspectives from organisations that have been through certification.
- Read the question and answer piece from the scheme operator on page 35.
- The case studies in appendix three may also give you some insight.

Appraise a piece of information for quality
- Go to Chapter Three and read about appraisal tools for printed and online information.
- Read the case study about using DISCERN and follow the link to an article on EQIP.

Develop a business case or an internal policy for quality information
- Read Chapter One, which gives the context to quality information and raises some of the key challenges and issues you will need to consider. You can use the parts of that chapter on the benefits of quality information as a starting point.
- Appendix one sets out the policy drivers for each UK country.
- If you are providing services to NHS patients then the part of Chapter Two on NHS requirements may also be useful.

Develop information about quality for users
- Read Chapter Four about appraisal for information users.
- Read the case study about evaluating cancer information, aimed at patients, family and friends on page 64.

Have your work externally recognised for its quality
- Read about award schemes for consumer health information on page 59.
- Read the information about quality marks for health information websites on page 48.
- Look at the part of Chapter Two about the Information Standard.
This guide is for people and organisations that produce health information for patients and the public. It can be used by any size of organisation, in any sector. It provides the reader with a comprehensive look at the subject of appraising health information.

Throughout the guide you will see symbols in the page margins. These are place markers to help you identify key points, case studies and personal perspectives:

- **KP** Key point
- **CS** Case study
- **P** Personal perspective

We are keen to hear what you think of the guide and to learn from you about any areas that we may not have covered. There is a form at the end of the guide to help you feedback your comments to us.

**Chapter One** puts quality and appraisal into context, exploring why quality is important and what it means in the world of consumer health information. There is information about the benefits of high quality information, for both users and producers, and some of the background that explains why quality has become a more prominent issue. Finally there is a look at general methods of appraisal.

**Chapter Two** explores the appraisal of processes used to develop consumer health information. This includes a broad look at tools that assess information development processes, the requirements of appraisal in the NHS and the Information Standard scheme that operates in England.

**Chapter Three** is about the tools available to information producers to help them appraise individual information resources. This includes tools for printed and online information, award schemes, guidelines and readability tools.

**Chapter Four** looks at appraisal for information users and explores the challenges of finding quality information, including searching the Internet. Tools for users are discussed, as are the pros and cons of using them.

Finally, there are four appendices that contain information on background subjects such as policy, the development of appraisal and other important schemes.
As information producers, we all know that quality is important. High quality health information for patients and the public is one of the most important aspects in the development and provision of materials and services. High quality means effective information, which meets the needs of users and which empowers them to make choices and take control of their health and wellbeing. The better the quality, the more useful, relevant and accessible the information is, and the more effective it will be in encouraging self-care, effective long-term condition management and healthy lifestyle choices.

Information users need the reassurance of knowing who and what they can trust, producers and providers need to be sure that their work is consistently meeting high standards. But how do information users and producers know what constitutes quality or how to recognise it when they see it? As consumer health information has become more prolific and widespread, the need to be able to understand, recognise and measure quality has grown.

It has become an important part of the work of information producers and a major issue for the public.

This guide is about appraising and assessing the quality of health information - whether that relates to a product or development process, or to a user or information producer’s definition of quality. It explores the key issues, looks at why we should measure quality and sets out the different appraisal tools and methods available to information producers and users.

This first chapter explores what quality means and why it is important to strive for it. It also explores the different methods available to any individual or organisation wishing to assess or appraise the quality of an information product or producer.

**Why is appraising quality important?**

The number of organisations in the UK alone that produce health information for the public is estimated to be around 60,000.¹ Add to these the number of organisations worldwide that can be accessed via the Internet and it is easy to understand why the average person feels overwhelmed with information and confused about what to trust and what to ignore.

When you add to the sheer volume of resources the fact that many of those searching for information will be under stress, anxious and unwell the importance of easily recognisable, high quality, trustworthy information becomes vital. Healthcare in the UK is undergoing major changes, seeing a shift away from the traditional ‘doctor knows best’ model to a new patient-centric model where individuals are increasingly likely to self-care, manage their long-term condition or take part in shared decision making with their health professional. Information, and access to it, lies at the centre of this shift so it is important that it effectively meets the needs of users and provides them with up-to-date, accurate information.

The needs of information users vary widely. Some people want to know the basics, or nothing at all, and others want to know everything.

Information comes in a number of forms - information that helps you to make a decision about treatment, factual information about a condition or operation, quality of life information and user generated information about services, health professionals and experiences, to name a few. Health information is now a vast and complex area and one which it takes skill and experience to navigate.

Information producing organisations vary in size and complexity, come from every sector and produce information on a vast array of conditions, services, treatments and lifestyle interventions. The information these organisations produce varies in content but also varies in quality. At one end of the spectrum is well planned information that is user-led, evidence based and balanced, at the other end is poor quality information that is biased, didactic, inaccurate and misinformed.

High quality information has the potential to do great good and is a vital part of any individual’s engagement with healthcare and health services.

It can lead to constructive dialogue with health professionals, encourage self-care, promote effective self-management and give individuals real control over their health. Research has explored the benefits of high quality information for patients and the public and concluded that good quality information can help to:

- prevent disease
- promote self-care
- inform treatment decisions
- improve the effectiveness of clinical care.

Conversely, poor quality information has the potential to do harm, though there is in fact little research available to demonstrate or quantify this. However, poor information has the potential to frighten, confuse and disengage the individual. It may falsely reassure people or worry them unnecessarily. At its worst, poor quality information may promote dangerous or harmful treatments, or lead to ill health or late diagnosis of serious conditions.

As more health information has become available to the public, from an increasing number of suppliers and through a growing variety of channels, concerns about quality have grown. These concerns have been raised by all of those with an interest in health information - information users, producers and policy makers.

**What is quality in the context of consumer health information?**

“Good quality health information is essential for greater patient involvement in healthcare. Patients and the public require information that is timely, relevant, reliable and easy to understand. This is an essential component of any strategy to promote self-care, choice, shared decision-making, medication adherence, self-management of chronic disease and health literacy.”

*Assessing the quality of information, Picker Institute Europe, 2006*

What constitutes a quality piece of information or a high quality process of developing information is something that has been discussed and tested many times over

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2 Coulter A, Ellins J, Swain, D. Assessing the quality of information to support people in making decisions about their health and healthcare. Picker Institute Europe. 2006

3 Crocco A G, Villasis-Keever M, Jadad AR. Analysis of cases of harm associated with use of health information on the Internet. JAMA 2002;287:2869-71
the past few decades, and is a concept that continues to be reassessed as the nature of consumer health information changes.

**KP** There is no one set of standards or guidelines accepted and recognised for use across the UK, for either individual information resources or the processes used to develop them. However, there are a number of key pieces of work that have influenced the debate about quality and helped in the creation of a set of quality benchmarks.

One of the first sets of quality standards for assessing individual resources came in the late 1990s from the Centre for Health Information Quality (CHIQ), a development agency working to raise standards in health information for the public. The centre offered a forerunner of The Information Standard, a logo called the Triangle Mark. The Triangle Mark was designed to represent three quality themes - information that was:

- **accurate** (up-to-date and evidence based)
- **clearly communicated**
- **relevant** (developed with consumers).

One of the first major reviews of the quality of individual resources was conducted by Coulter et al and published in 1999. The study explored shared decision making and the information patients use to support the choices they make. The research examined information for patients on 10 topics such as back pain, hip replacement and infertility. The study highlighted many deficiencies in the information available. The authors suggested a checklist for quality content (see Box 1 overleaf) and a number of ways to raise the quality of individual information resources, including:

- **Tell the full story** - create information that is honest and balanced and cover information about the effectiveness of treatments and procedures, including side-effects.
- **Include topics that are relevant to patients** - this means involving users before the information is developed to find out what their needs are.
- **Be comprehensive and cover all options, including those without a clear evidence base.**

**Deal with uncertainty** - where clinical opinion varies or where evidence is not certain say so, and be clear about the sources of evidence used to support the information given.

**Put a date on the information and review and amend it regularly.**

**Write text that is ‘honestly optimistic’, clear and concise.**

**Empower the reader and help them to make choices.**

The authors concluded that there is a great deal more to the production of good quality patient information than is commonly assumed. They highlighted three key elements of quality information resources - patient involvement in the development, the use of reliable evidence, and care about the purpose of the information and the needs of the target audience. These elements closely reflect those used as the benchmark for the CHIQ Triangle Mark.

Since then tools such as DISCERN, the guide to developing patient information from the King’s Fund and criteria such as that used to...
judge the British Medical Association (BMA) Patient Information Awards have collectively added to the informal list of standards that demonstrate a piece of quality information (see Chapter Three for more information about all of these resources).

Although there is not one set of golden rules, agreed by all, that can be applied to every resource and development process, there are some key factors on which consensus has been reached. Some of the main ones are that information and processes should be:

**Accurate and reliable** - factually correct and consistent, produced by an individual or organisation with appropriate qualifications.

**Accessible** - a range of formats, effectively disseminated, pitched at the right level.

**Relevant** - targeted to its audience, users are involved in development and production.

**Evidence based**

**Comprehensive** - covers all aspects.

**Current** - with a date of publication and review.

**Readable** - easy to read, informal, active.

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**Box 1 Checklist for developing quality content:**

1. Use patients’ questions as the starting point
2. Ensure that common concerns and misconceptions are addressed
3. Refer to all relevant treatment or management options
4. Include honest information about benefits and risks
5. Include quantitative information where possible
6. Include checklists and questions to ask the doctor
7. Include sources of further information
8. Use non-alarmist, non-patronising language in active rather than passive voice
9. Design should be structured and concise with good illustrations
10. Be explicit about authorship and sponsorship
11. Include reference to sources and strength of evidence
12. Include the publication date

Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? BMJ, 1999; 318:p.318-322
Many of the standards applied to individual resources can also be applied to the processes used to develop information, for example making sure that the evidence base is firm and consistent and involving users. The main quality standard that can be applied to the process of developing information is The Information Standard certification scheme for information producers in England. This has been influenced by projects like DISCERN, Health on the Net and the International Patient Decision Aid Standards Collaboration.

What are the benefits for information producers of developing quality health information, and of appraising it?

**Organisational pride and external respect from peers** - improving the quality of information resources and processes can engender a sense of pride and satisfaction among staff. It can also earn the respect of other organisations.

**Wider use of their information resources** - by producing high quality information and by developing a trusted brand, information producers may encourage more people to make use of their resources.

**‘Recommendation’ from health professionals** - health professionals are one of the major influencers of patient and public behaviour and act as a gateway to health information for many people. By producing easily recognised and reliable high quality information, producers may encourage health professionals to use and recommend their resources.

**Increased income generation or profile** - producers could gain public recognition, which may lead to a higher profile, increased awareness of the organisation and its services and result in an increase in supporters, service users and funds.

**Commercial advantages** - consumer health information is operating in a more commercial environment. Appraised resources or organisations shown to be of high quality are more likely to be used by commissioning organisations or businesses.
Reducing costs - high quality information may encourage more people to self-care or self-manage, or lead to behaviour change and the prevention of illness, which has the potential to reduce NHS costs across many areas, both in the short and long-term.

What are the benefits for information users of choosing high quality health information?

- **Puts power and control in the hands of the individual** - good information gives a sense of empowerment and understanding.
- **Helps people to feel confident about the choices they make.**
- **Positively influences conversations with health professionals** - helps shared decision making, gives patients confidence and the information they need to ask questions.
- **The reassurance of resources that can be trusted at a time when an individual may already be under stress and feel anxious.**

Fast and easy access to information - being able to recognise a quality piece of information, or organisation, straightaway cuts down the time and energy needed to search for information.

Less need to consult a health professional for information - good information supports self-care and self-management, which may mean people have less need to see their health professional.

What are the challenges of appraising quality?

There are some fundamental questions that information producers must ask themselves about the search for ‘quality’ and the development of tools and systems to appraise it. There are no easy answers and appraising information is not always straightforward. When thinking about information appraisal or quality there are a number of issues to consider. These may help you to decide which route is best for you, or your organisation, to take and help you choose appraisal methods and tools.

a) Whose definition of quality are you interested in?
b) Is it really possible to accurately assess and measure quality and if so, do you really need to? Does it ultimately matter, particularly to information users?
c) Improving quality has costs attached to it - financially and in terms of time. Every organisation has finite resources - where do you draw the line on the quality scale?
d) The person making the final judgement on quality is the end user - therefore they have to be equipped to make a judgement. Either patients and the public need to have critical appraisal skills to help them decide, or they need to recognise a quality mark and know what it stands for. Can you help them to do this?
Why has assessing the quality of health information become important?

“Everybody gets so much information all day long that they lose their common sense.”
Gertrude Stein, writer, 1874-1946.

Major changes are taking place in the health environment, which are driving Governments, policy makers and information producers to confront and tackle the issue of quality. The Central Office of Information (COI) calls these major changes ‘mega-trends’. The Department of Health in England developed an accreditation scheme for health information in an attempt to address three major trends in society:

Medical advances - the speed at which medical science is advancing, which means treatment options change more frequently and there are more treatments available.

Information overload - too much information makes decision making harder.

A shift towards choice - there is an increasing emphasis on choice in all areas of life, so consumers face increasingly complex decisions about their health and social care.

Perhaps the biggest impact on consumer health information, and on quality, in the last decade has come from the growth in use of the Internet. Home Internet access across the UK has increased from just over 30% in 2000 to 70% in 2009. Research from the United States shows that four-fifths of Internet users go online to look for health information. If this is reflected in the UK then around 30 million people in the UK are looking for and accessing health information in this way. It is probably true to say that the Internet is one of the key, if not the key, medium for providing health information. However, it is worth remembering that although an increasing number of people are accessing health information on the Internet, some of the groups who are most in need of good quality information are the least likely to be accessing information this way, for example, older people, people from ethnic minority groups and people from low income groups.
This increasing use of the Internet has led to ongoing concern about the overall quality of health information found on it. There seems to be a belief that by reading and then using the health information found on websites patients and the public have come to some harm. Yet there does not seem to be much proof of this. A systematic review carried out in 2002 could find little evidence to support the theory. The quality problems related to web-based information appear to be the same as for other types of information, i.e. the variability of quality.

There are some specific quality issues about online health information, in addition to the usual quality concerns. These relate to the accessibility of information on websites - can people effectively navigate around the Internet and websites to find what they need? The Internet is also evolving at speed. Web tools now allow users to collaborate and share information about health, which has led to a new kind of information - self-generated content. Changes in web technology have meant that even those who have a basic understanding of information technology can now add their own online content, which is giving people the opportunity to build a collective wisdom that can add significantly to medical opinion about areas like the side-effects of medicines and rare conditions. These changes have an impact on both the public’s and the information producer’s view of quality.

Information is at its most effective when it is tailored and can be accessed interactively (so people can build up a ‘package’ of information to suit their needs). The Internet has the possibility to do both of these, more so than any other medium. This adds a potentially new quality standard to the mix.

Appraising quality

“Quality means doing it right when no one is looking.”

Henry Ford, Engineer and Businessman, 1863-1947

When it comes to appraising the quality of either your own work, or that of another organisation there are two routes open to you - the formal and the informal. Formal methods are usually about applying criteria developed by an accrediting organisation, informal methods rely on self-appraisal. The same applies for information users.

Information producers

If you want to appraise your own work two options lie open to you (you may want to do either or both of these):

Informal appraisal - develop your own internal checklists, processes and policies based on good practice and your own organisation’s needs and priorities.

Formal appraisal - use an external appraiser to assess your processes or resources and give a quality mark, or use appraisal tools and standards developed by an accreditation organisation and apply them to your work.

If you are appraising another organisation’s work or processes, there are three main options open to you:

1. Look for the quality marks of accreditation schemes and standards on materials and decide whether these standards meet your requirements.

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2. Use appraisal tools, such as DISCERN, to appraise individual resources.

3. Apply your own internal standards to the information or organisation to see whether they meet your quality standards.

**Information users**

Users can appraise the quality of the information they read, watch and listen to by:

- Looking for the quality marks of accreditation schemes and standards on materials (users will need to know what they mean).
- Use their own informal quality checklist, based on factors such as what they know about the information producer, how the information looks, what it says and who wrote it.

**Formal appraisal**

Anything or anyone can be appraised or evaluated - products, equipment, people, management systems or whole organisations. The UK’s accreditation body, the United Kingdom Accreditation Service (UKAS, www.ukas.com), says that the reason for getting something independently appraised or evaluated is usually to confirm it meets specific requirements in order to reduce risks - for example, to protect a company’s reputation or to meet legal requirements. In the case of consumer health information independent, formal appraisal could reduce an organisation’s legal risk, under NHS Litigation Authority requirements, for example. There are two types of appraisal/accreditation schemes:

- Those that examine and assess products. Product accreditation schemes show that a product conforms to specific standards and often use a public facing logo or quality mark that demonstrates this to the consumer. An example is the British Standards Institute Kitemark®.
- Those that examine and assess the process used to develop a product or resource. Process accreditation schemes show that an organisation’s process conforms to specific standards, or that their products are produced using processes that conform to specific standards. An example is The Information Standard.

The appraisal of a product is sometimes called an ‘archaeological’ approach whereas the appraisal of process is sometimes called an ‘architectural’ approach.

Consumers have become a lot more ‘savvy’ about the products they buy and the services they use. The marketplace has responded by creating a range of accreditation schemes and quality marks, including Fairtrade and the Lion Mark on eggs (see Box 2 for details). Quality marking schemes are designed to limit the need for consumers to assess a product or piece of information themselves, by encouraging the producer to rate what they produce or comply with certain codes of conduct. Some marks and schemes rely on producers self assessing and certifying, whereas others use a third party to rate products. Producers and service providers have also responded by developing ‘charters’ - statements of what the consumer as passenger, patient or parent, etc should expect.

Quality marks have been developed for consumer health information and health information websites. These are discussed in more detail in Chapter Three, which looks at appraising resources.
Chapter One: Putting quality and appraisal into context

Box 2 Quality Mark examples:

**Kitemark** was the first product and service quality mark to be established in the UK and was created by the British Standards Institute over 100 years ago. Kitemark aims to reassure consumers that vital safety and performance requirements have been met on a wide range of products and services. From electrical contractors to double glazed windows and installation; from fire extinguishers to cattle ear tags and glass; a Kitemark provides a visible confirmation of quality. Kitemark’s website states that the symbol is recognised and trusted by over 88% of the UK population. [www.kitemark.com](http://www.kitemark.com)

**The Lion Mark** denotes eggs produced to a stringent Code of Practice incorporating the latest research and advice on Salmonella and eggs from scientists and vets. British Lion eggs account for around 85% of UK egg production. It shows that the eggs have been produced to the highest standards of food safety. [www.lioneggs.co.uk](http://www.lioneggs.co.uk)

**FAIRTRADE Mark** is a registered certification label for products sourced from producers in developing countries. For a product to display the FAIRTRADE Mark it must meet international Fairtrade standards. The mark ensures disadvantaged farmers and workers in developing countries get a better deal. Their research claims that 72% of the UK public now recognise the FAIRTRADE Mark. [www.fairtrade.org.uk](http://www.fairtrade.org.uk)

**TrustMark** helps people find reliable, trustworthy tradesmen to make improvements and repairs inside and outside the home. TrustMark is a not for profit organisation supported by Government, the building industry, retailers and consumer protection groups. [www.trustmark.org.uk](http://www.trustmark.org.uk)
Whatever the type of scheme, quality marking does have pitfalls:

• It relies on the quality scheme being robust and respected, and some schemes are not - products or services may still be of poor quality even though they have been quality marked.

• Voluntary adoption of codes of conduct or quality marks has the potential for fraudulent use by producers.

• It can be expensive.

• There is no guarantee that consumers will recognise a quality mark or that it will influence their decision making.

• There is very little independent research on the impact of quality marking and accreditation.

• The organisations awarding quality marks have to maintain a high level of trust at all times to give value to the mark.

**Informal appraisal**

Most information producers informally appraise their own materials on a regular basis, when they develop, evaluate and review their own information. By using checklists, information policies, development tools and procedures many producers already have quality standards in place which ensure that information leaving the organisation is of a high standard and is consistent and relevant. Many information producers are justifiably proud of the systems and guidance they have in place to safeguard quality.

These informal methods have an important part to play and should not be ignored or disregarded. They can be robust and thorough and form the foundations of high quality information services. Informal appraisal methods have often been developed and refined over time to meet the specific needs of an organisation. They are usually collaborative and are influenced by good practice from other organisations.

Because information staff are involved in the development of this kind of information appraisal they may be more likely to feel ownership of it, to use it and to see it as relevant to their work.

However, sometimes informal appraisal is not enough, either for the organisation itself or for those using its services. In an increasingly crowded and competitive consumer health information market undertaking formal methods of appraisal may be seen as an important strategy to get noticed, to be competitive and to reach out to patients and the public. From the information users point of view these schemes have the potential to highlight good information and to reassure.

The remaining chapters of this guide explore the methods of formal quality appraisal open to both information producers and users. It explores how to apply them and looks at some of the pros and cons.
Background

One approach to appraisal is examining the processes by which information is developed, rather than looking at individual materials. However until very recently, with the development of The Information Standard in England, there have been few tools or standards available to help information producers assess and develop their processes.

In 2005 the International Patient Decision Aid Standards Collaboration (IPDAS) published checklists for assessing the quality of decision aids, including a checklist for the process of development. Decision aids are tools that present benefits and risks in enough detail for patients to be able to use them in the decision making process. They are often tailored to the individual’s health status and help them to make specific choices about their treatment.

The IPDAS checklist covered a number of areas that the developers felt were important, including having a systematic process, using evidence based information and making clear any conflicts of interest (see Box 3 overleaf). However, the checklist is of limited use for many producers as it focuses only on decision aids.
Box 3 IPDAS Checklist 2005. Does the decision aid...

**Present information in a balanced manner?**
- Able to compare negative/positive features of options.
- Shows negative/positive features with equal detail (fonts, order, display of statistics etc).

**Have a systematic development process?**
- Included the developer’s credentials/ qualifications.
- Finds out what users (patients/practitioners) need to discuss options.
- Has peer review by patient/professional experts not involved in development and field testing.
- Is field tested with users (patients facing the decision/practitioners presenting options).
- The field tests with users (patient/practitioner) show the decision aid is acceptable, balanced for undecided patients and understood by those with limited reading skills.

**Use up to date scientific evidence that is cited in a reference section or technical document?**
- Provides references to evidence used.
- Reports steps to find, appraise, summarise evidence.
- Report date of last update.
- Report how often decision aid is updated.
- Describe quality of scientific evidence (including lack of evidence).

- Uses evidence from studies similar to those of target audience.

**Disclose conflict of interest?**
- Report source of funding to develop and distribute the patient decision aid.
- Report whether authors or their affiliations stand to gain or lose by choices patients make after using the patient decision aid.

**Use plain language?**
- Is written at a level that can be understood by the majority of patients in the target group.
- Is written at grade 8 equivalent or less according to readability score (SMOG or FRY).
- Provides ways to help patients understand information other than reading (audio, video, in-person discussion).

When carrying out research on the quality of health information in 2006, researchers from Picker Institute Europe made a number of changes to the checklist and used it as part of their assessment of information producers processes (see Box 4 overleaf). These changes included the addition of some extra usability criteria and a section on dissemination, which the researchers felt was an important aspect of quality information provision.
### Chapter Two: Appraisal for information producers: the development process

**Box 4 Revised IPDAS checklist.** Picker Institute Europe 2006.

Do the Information providers...

<table>
<thead>
<tr>
<th>Use a systematic development process?</th>
<th>10 points</th>
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</thead>
<tbody>
<tr>
<td>Finds out what information users (e.g. patients, carers, professionals) need to discuss options or decide on courses of action</td>
<td></td>
</tr>
<tr>
<td>Involves users throughout the development process (e.g. assessing information needs, selecting topics)</td>
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<tr>
<td>Has materials field tested by patients/carers not involved in development</td>
<td></td>
</tr>
<tr>
<td>Has materials peer reviewed by patients/carers not involved in development</td>
<td></td>
</tr>
<tr>
<td>Has materials reviewed by professional experts not involved in development</td>
<td></td>
</tr>
<tr>
<td>If necessary, revise materials based on field testing and/or peer review</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Use up to date scientific evidence?</th>
<th>10 points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reviews the clinical research evidence and use systematic reviews where available</td>
<td></td>
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<tr>
<td>Has a procedure for regularly revising and updating information</td>
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</table>

<table>
<thead>
<tr>
<th>Address usability issues?</th>
<th>5 points</th>
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<tbody>
<tr>
<td>Written at a level that can be understood by the majority of patients in the target group (e.g. tested using SMOG/Fry, received Crystal Mark or produced a glossary?)</td>
<td></td>
</tr>
<tr>
<td>Provides additional ways to help patients understand the information other than reading (e.g. audio, video)</td>
<td></td>
</tr>
<tr>
<td>Field testing involves groups of patients with different needs and abilities</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Have a dissemination plan?</th>
<th>5 points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan for how users will access the information</td>
<td></td>
</tr>
<tr>
<td>Plan for how clinicians will be informed about it</td>
<td></td>
</tr>
<tr>
<td>Plan for integrating it into clinical care</td>
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</table>

**Total score for development (out of 30)**

<table>
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<tr>
<th>Bonus Point</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Produces translated materials in non-English languages</td>
<td></td>
</tr>
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</table>
The amended checklist was used as part of the Picker Institute Europe review of the practices of a range of information producers. The results of the research project showed that information producers differed substantially in their processes:

- In general, smaller organisations met fewer criteria than larger ones, regardless of the sector they were in.
- Organisations whose sole purpose was the production of information also scored higher, compared to those for whom information was a smaller part of their remit.
- Procedures varied widely in other areas, such as user involvement, evidence based information and readability of materials.

The lowest scores across the board were for the dissemination of information - a key part of the information production process.

The results of their research formed part of the report ‘Assessing the quality of information to support people in making decisions about their health and healthcare.’

The main findings from the study were:

**Four fifths of patients actively seek information about their health.** The sources they use vary. Most get information from their doctor, but many also use the Internet, books, the media and patient organisations.

**The estimated number of organisations in the UK that provide health and social care information for patients and the public is 60,000.**

**There were wide variations in the quality of information materials.** Materials tended to score reasonably well on clarity of structure and layout, but they performed significantly worse in relation to the provision of accurate, reliable and sufficiently detailed clinical information to assist patients in decision making.

**Most respondents to the research survey reacted positively to the idea of an information accreditation scheme.** Perceived advantages included raising quality standards in patient information provision, increased revenue for information providers, enhanced trust among health professionals, greater use of information by patients and the public, and improving the image of information providers.

The report concluded that good quality health information is essential for greater patient involvement in healthcare, but the quality of patient information materials needed to be improved. The report authors suggested that an information accreditation scheme could help to raise quality standards.

One of the major criticisms directed at schemes that assess the quality of development processes is that an excellent process does not necessarily equate to the development of high quality materials.

Another part of the Picker Institute Europe research examined the content of information materials produced by the same organisations that were interviewed about their processes. There was a weak, non-significant correlation between scores achieved for the content of materials and development processes. The Picker Institute Europe report says the following about this:

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“Some providers who scored high on the content of their materials did not score well on the development process, and some of those whose materials failed to reach the standard, nevertheless claimed to have a relatively high quality development process. Once again, we would stress the need for caution in interpreting these results. While we believe our assessment of the content of the materials was reasonably systematic and reliable, the same may not be true of providers’ accounts of their development process.”

“As examples of the types of discrepancies that arose, at one extreme was the small voluntary organisation where no users were involved in the development process, the informant was unable to specify where they found their clinical evidence, their materials were targeted towards educated readers and they weren’t concerned about making them accessible to less literate groups, and they had nothing approximating a dissemination strategy. Yet the content of their leaflet achieved a good score and a high ranking. At the other end of the scale, a large public sector organisation achieved a very high ranking in respect of their account of the development process, but much lower in terms of content assessment. This underscores the importance of an accreditation system assessing both the development process and the information content.”


**NHS Requirements**

The four countries of the UK have different requirements for Trusts and Health Boards relating to the appraisal of health information development processes. Some of these are mandatory, others act as guidance for information producers.

**England**

NHS Trusts in England are required to have the information they produce for patients appraised via two main channels - the Care Quality Commission Standards and the NHS Litigation Authority (NHSLA) requirements.

**Care Quality Commission (formerly the Healthcare Commission)**

The need to provide information was highlighted as a priority in National Standards, Local Action, the Health and Social Care Standards and Planning Framework for 2005/6 - 2007/8, which set out national care standards (both core and development) that all NHS organisations should achieve. The three main standards covered systems to ensure the quality and provision of information to the public, that allowed them to provide feedback and helped them to make choices around complaints, treatments and services.

The Healthcare Commission was charged with assessing whether Trusts were meeting the standards, and from 2006 introduced an Annual Health Check.

Trusts had to declare their compliance with the core standards set out in Standards for Better Health. The standards were self assessed by Trusts with random checks carried out by the Care Quality Commission.

In proving that they met the standards, Trusts were required to appraise the information they produced and the systems they had in place to produce it.

As of April 2010, health and adult social care providers must register with the Care Quality Commission in order to be able to operate. In order to register, they must show that they are meeting a wide range of essential standards of safety and quality set out under the Health and Social Care Act 2008 Regulations 2009. New guidance for registration is undergoing consultation at the time of writing. The first of the proposed new regulations is about involvement and information. It looks at what providers should do to make sure that people using services are involved in making decisions about their care, treatment and support. It also looks at the information that providers should make available to people so that they know what their rights are, and they are able to make informed choices.

Regulation 15, Respecting and involving service users, is where information for patients and the public is covered.

Among other requirements, organisations are expected to:

- provide service users with appropriate information and support in relation to their care or treatment.
- encourage service users, or those acting on their behalf, to understand the care or treatment choices available to them, and discuss with an appropriate healthcare professional, or other appropriate person, the balance of risks and benefits involved in any particular course of care or treatment.

To meet these outcomes registered organisations are expected to provide information to patients about their care, treatment and support, and their rights, in a way that they can understand.

NHS Litigation Authority

The NHSLA manages schemes to indemnify NHS organisations against clinical and non-clinical negligence claims. There are NHSLA risk management standards for each type of NHS healthcare organisation, designed to address organisational, clinical, and non-clinical health and safety risks. All NHS acute and specialist hospital Trusts, Primary Care Trusts (PCTs) and independent sector providers of NHS care are required to be assessed against these standards.

Members of the scheme are assessed every year and the information is used to calculate the level of risk that each Trust faces. Discounts are available to those Trusts that comply with clinical risk management standards and to those with a good claims history.

The standards aim to encourage Trusts to make sure that their systems of care are well planned and managed so that the risk of incidents is reduced.

The standards are set at three different levels through which Trusts may progress. At level one the Trust has to demonstrate that they have an approved policy (for a particular aspect), at level two the policy has been implemented and at level three the policy can be shown (through audit, etc) to be embedded and to be working within the Trust. There are specific standards that relate to health information (see Box 5 overleaf).
Box 5 Acute Trust, PCT, Mental Health, Learning Disability and Independent Sector Standards
(Maternity services have slightly different standards)

Standard 4: Clinical care

Level One
The organisation has approved documentation which describes the process for developing patient/service user information associated with care, treatments and procedures. As a minimum, the approved documentation must include a description of the:

- process for the development of patient/service user information
- list of the essential content to be included in leaflets or other media i.e. risks, benefits and alternatives, where appropriate
- reviewing process, including review date
- archiving arrangements
- process for monitoring compliance with all of the above.

Level Two
The organisation can demonstrate implementation of the approved documentation which describes the process for developing patient/service user information associated with care, treatments and procedures. The organisation can demonstrate compliance with the objectives set out within the approved documentation described at Level 1, in relation to the:

- list of the essential content to be included in leaflets or other media i.e. risks, benefits and alternatives, where appropriate
- archiving arrangements.

Level Three
The organisation can demonstrate that there are processes in place to monitor compliance with the approved documentation which describes the process for developing patient/service user information associated with care, treatments and procedure.

The organisation can demonstrate that it is monitoring compliance with the minimum requirements contained within the approved documentation described at Level 1, in relation to the:

- list of the essential content to be included in leaflets or other media i.e. risks, benefits and alternatives, where appropriate
- archiving arrangements.

KP NHS Organisations that have achieved The Information Standard certification will automatically achieve level three NHSLA requirements.
Guy’s and St Thomas’ NHS Foundation Trust

Appraising patient information

Guy’s and St Thomas’ NHS Foundation Trust has produced guidelines for the appraisal of patient information to meet NHSLA requirements. This has meant introducing Trust-wide processes for approving, storing and disseminating information - an ambitious aim for a Trust with 10,000 employees, and 800,000 patient contacts per year.

Responsibility for co-ordinating this work lies with the Patient Information Team (for externally sourced material) and Communications (Publications) Team (for internally produced materials). Over 2007 - 2008, these teams created a guide for staff which is available on the Trust Intranet. This guide explains how to write or select information and directs staff to relevant submission forms.

Submission forms require staff to obtain approval for medical content from appropriate clinical staff and of medications-related content from the Trust’s Medicine’s Information Service. The forms also cover readability, accessibility and risk management, including:

- clarity of structure and purpose
- explanations of risks, benefits and alternatives to treatments and services
- consent requirements
- explanations of complicated words or jargon
- consideration of equality and diversity impacts.

These guidelines were drawn up on the basis of information and advice from internal experts (e.g. Assurance and Language Support Services) and from the Royal National Institute of Blind People (RNIB).

To promote service user involvement, all internally produced leaflets are reviewed by patients or members of the public. Samples of externally sourced information are shown to the Trust’s Patient Information Users’ Group to elicit their views.

Each clinical directorate is represented on a Trust-wide Patient Publications Group (PPG), which meets quarterly to share experiences and good practice, and to monitor patient information work. The PPG is accountable to the Trust’s Clinical Governance and Risk Management Committee, by collecting data and submitting bi-annual reports.

Guy’s and St Thomas’ attained NHSLA Level 2 in December 2008 and is currently working towards Level 3.

For more details, or for copies of policies and guidelines, contact Rachael at: rachael.twomey@gstt.nhs.uk
As far as the assessment is concerned, Trusts have to send electronic evidence in advance of the assessment date. In my Trust, the assessors were with us for two full days.

I had to provide some approved information leaflets on ‘risky’ procedures (e.g. aneurysm repair) and common surgical procedures (for example, laparoscopic hernia repair). The assessors were very interested in how we archived our information (so that we could show version control, etc) and sat with me at my desk whilst I ‘walked’ them through the process. In addition to the information sheets, policy etc that I had provided as evidence, they randomly picked information sheets out from our electronic database which they checked for content around risks, benefits and alternatives.

Interestingly, the report that the Trust gets afterwards only details non-compliant elements so that when it came to demonstrate (for The Information Standard) that our patient information policy was compliant at level 2, the only thing I could give them was that patient information was not listed in the report!

For more information contact Katrina at katrina.glaister@salisbury.nhs.uk

Wales

The standards ‘Doing Well, Doing Better: Standards for Health Services in Wales’ require health services in all healthcare settings to ensure they comply with the standards to make improvements to their services. There is a specific standard relating to information and this is then supported with further guidance, which is currently being developed, although drafts are available.

Patient Information and Consent

Organisations and services recognise and address the needs of patients, service users and their carers by:

a) providing timely and accessible information on their condition, care, medication, treatment and support arrangements;
b) providing opportunities to discuss and agree options;
c) treating their information confidentially;
d) obtaining informed consent, in line with best practice guidance;
e) assessing and caring for them in line with the Mental Capacity Act 2005 when appropriate.
Chapter Two:
Appraisal for information producers: the development process

The Standards: www.nhswalesgovernance.com
Supporting Guidance: www.nhswalesgovernance.com

Organisations self-assess against the standards on an annual basis and these are subject to external validation by Healthcare Inspectorate Wales. They are currently revising their assessment processes and hence, this approach is likely to change in the future - see their website for more information: www.hiw.org.uk

Scotland
NHS Scotland is currently exploring quality standards as part of the development of their information and support service, NHS Inform. A quality working group has been established to look at the development of standards.
In addition, NHS Quality Improvement Scotland contains two standards that relate to consumer health information:13

Standard 2: The Health, Wellbeing and Care Standard - NHS QIS Clinical Governance and Risk Management Standards
2a.1 Information on services provided by the NHS Board is available to patients, carers and the public.
2a.6 Patients, and with their consent, carers, are provided with a range of information about their condition, treatment options, outcomes, risks, side effects and rights on an on-going basis.
www.nhshealthquality.org

Northern Ireland
In 2006, Department of Health, Social Services and Public Safety (DHSSPS) published Quality Standards for Health and Social Care, Supporting good governance and best practice.14

The Quality Standards for Health and Social Care set out the standards that people can expect from Health and Personal Social Services (HPSS) in Northern Ireland. The standards are used by the Regulation and Quality Improvement Authority to assess the quality of care provided.

Each NHS organisation has a legal responsibility for satisfying itself that the quality of care it commissions and/or provides meets a required standard.

These standards have five key quality themes, one of which is Effective Information and Communication. The standards are described as ‘essential’ - the absolute minimum to ensure safe and effective practice, or ‘developmental’ - designed to encourage and support a move to better practice.

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These are some of the essential standards that relate to consumer health information:

- active participation of service users and carers and the wider public.
- an effective information strategy and communication strategy
- clear communication principles for staff and service users, which include:
  - openness and honesty
  - use of appropriate language and diversity in methods of communication
  - sensitivity and understanding
  - effective listening
  - provision of feedback.
- clear information principles for staff and service users, which include:
  - person-centred information
  - integration of systems
  - delivery of management information from operational systems
  - security and confidentiality of information
  - sharing of information across the HPSS, as appropriate.
- a range of published up-to-date information about services, conditions, treatment, care and support options available, and how to access them both in and out of service hours, which are subject to regular audit and review.

To see a copy of the standards go to: www.dhsspsni.gov.uk
The Information Standard

The information gained from the Picker Institute Europe report, 2006 and from organisations like the Centre for Health Information Quality, DISCERN and other guidelines, codes of practice and standards, provided the beginnings of an Information Accreditation Scheme Standard. A draft standard underwent stakeholder consultation with views sought from potential certification bodies, information producers and other interested parties.

Once the consultation period was completed, the development process continued, to include exploring and developing support arrangements, marketing and branding, models for the scheme ownership and engagement of certification bodies. Following ministerial approval the scheme entered a testing phase, recently completed at the time of writing. The accreditation scheme, now called The Information Standard launched in November 2009.

What is the Information Standard?

The Information Standard is essentially a certification scheme and quality mark for health and social care information producers. The Scheme is owned by the Department of Health (DH) in England and operated by Capita. The Information Standard evaluates the processes that producers use to develop information, rather than individual information materials. The aims of the Standard are to:

- Provide an effective way for people to make judgements about information to support decisions regarding their lifestyle and care.
- Support information producers in raising the general standard and reliability of information they provide to the public.

If you apply to the scheme, a certification body will evaluate the methods and systems you use to produce your information against the criteria required by the Information Standard. As part of the process a sample of your information will be evaluated.

This sample is selected by your certification body at the start of the assessment process. The people auditing your resources follow a set of guidelines to ensure that a common approach is used for all organisations.

If your organisation passes the accreditation process you become certified and are able to use the Information Standard logo on your materials. This demonstrates to members of the public that the information they are using is of a high standard, and can be trusted.

The scheme is open to health and/or social care information producers across the public, not-for-profit and commercial sectors. Participation in the scheme is voluntary. Organisations applying for certification pay a fee for the assessment.

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15 Assessing the quality of information to support people in making decisions about their health and healthcare. Picker Institute Europe. 2006. www.pickereurope.org
What is in the Information Standard?

The Standard sets out the criteria that information producers will need to satisfy in order to be certificated. There are requirements in five areas:

Commitment and how you will deliver what is required - internal policy commitment to the scheme and its standards.

Aims of information production - engaging staff and volunteers and lead responsibilities for information production, including how information fits into the other activities and aims of your organisation, the training and skills of staff involved in information production and accountability.

Methods and systems used to produce information materials that meet the requirements set out - establishing your processes and policies for producing information, including document control; identifying your target audience; ensuring information is accurate, easy to use, impartial and user tested; and the use of outsourced services.

Audit of information production systems - how you will ensure that processes are maintained and how you will monitor that you are complying with the Standard.

Corrective action - how you will deal with errors in information resources and how long it will take you to do this.

Guidance notes accompany the Information Standard which demonstrates what you need to do in order to pass the certification process. The criteria are assessed when you are visited by the certification body as part of the certification process. The Information Standard website contains a ‘road map’ for organisations that are interested in applying for the Standard ([www.theinformationstandard.org](http://www.theinformationstandard.org)). This has ten steps which will take you from thinking about applying for the standard, through to certification.

How does the certification process work?

Scheme rules set out the certification process and how it works, and outlines the responsibilities of all parties in the process. They are available on the Information Standard website.

There are five key steps in the assessment process that organisations must follow.

1. **Pre-application** - you assess your readiness for any application and decide how and whether to proceed.

2. **Application** - you complete the application form and submit it, along with other documents that support the application, to the certification body you have chosen.

3. **Evaluation** - you receive an onsite visit from the certification body which assesses your methods and systems for producing information. After the visit you might need to make changes to your systems. A sample of your information materials will be assessed by specialists and following this an evaluation report will be produced.

4. **Certification decision** - based on the information in the evaluation report you will be certified and will then be entitled to use the quality mark on your materials.

5. **Surveillance and reassessment** - certification lasts for three years. During this time, the certification body will conduct interim assessments every year.
Chapter Two: 
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Your route to certification

<table>
<thead>
<tr>
<th>First point of contact</th>
<th>Getting started and preparing to apply</th>
<th>Assessment and certification</th>
<th>Impact</th>
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</thead>
<tbody>
<tr>
<td><strong>Point of contact</strong></td>
<td><strong>Completing the online tools</strong></td>
<td><strong>Approach a certification body</strong></td>
<td>• Improved processes</td>
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<tr>
<td>Website</td>
<td>Roadmap</td>
<td></td>
<td>• Increased efficiency</td>
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<td></td>
<td>Guide to Certification</td>
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<td>• Higher profile</td>
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<td></td>
<td>Self assessment</td>
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<td>• Greater reach and credibility</td>
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<tr>
<td>Call centre</td>
<td>Tools to help spread the word in your organisation</td>
<td>On-site assessment</td>
<td>• Use of the mark</td>
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<td></td>
<td>Attend training day</td>
<td></td>
<td>• Evaluation report</td>
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<tr>
<td></td>
<td>Tools to build your business case</td>
<td></td>
<td>• Dealing with non-conformities</td>
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<tr>
<td></td>
<td>Look at your current process</td>
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<td>• Certification</td>
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<td>Involve other staff</td>
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Support through the journey

- Regular newsletters
- Dedicated Information Producer Support Manager
- Regularly updated website
- Included on Members' register

Reproduced by kind permission of Capita and the Information Standard.
Andrew Neighbour, Operations Director at Capita, the Information Standard scheme operators, answers some of the questions Patient Information Forum (PiF) members have raised about the scheme.

Q1 - Many organisations will be weighing up the pros and cons of applying to the scheme, particularly small organisations. Why do you believe the Information Standard is worthwhile?

The Information Standard acts as a powerful tool for positive change within an organisation. It will enhance an organisation’s credibility as well as reputation and profile. Association with the scheme will help promote the organisation, as the scheme will be promoted to both information producers and the public. It will:

- demonstrate excellence in the production of patient information and will add brand value and reinforce brand positioning.
- help improve internal information production processes as well as providing a comprehensive framework for continual improvement.
- contribute to the bigger picture objective of raising information standards across the board.
- demonstrates commitment to being a customer focused organisation.

We are aware that smaller organisations will require specific support to achieve certification and we have therefore put in place support measures - both financial and practical - to help them.

Q2 - What would you say to people who argue that the Information Standard is a top down approach to appraising information - telling the public what is good information and what is not, rather than being user led?

Many reports have found that despite the plethora of health information available on the web and elsewhere, patients and members of the public find it difficult to know what to trust. The Information Standard is based on extensive research into people’s health information needs. These include a 2007 Healthcare Commission Patient Survey, a Department of Health Information Prescriptions survey from 2008, and the 2006 Picker Institute Europe report. These can be found on the Department of Health website. The scheme is overseen by an Executive Council that includes user representatives, and users are also well represented on the Engagement and Development Board.

Q3 - How will you be engaging with information producers to encourage take up of the scheme, particularly NHS Trusts?

We have a target list of 15-20 early adopters who have been approached about joining the scheme. These organisations are the market leaders in their area and their membership will encourage others to join. For NHS Trusts, over fifty attended the launch and they remain a key target for membership of the scheme. We have agreed to work with
the NHS Litigation Authority (NHSLA) so that membership of the Information Standard is deemed to satisfy their requirement for producing patient information. Finally, several founder members of the scheme have agreed to act as a mentor to NHS Trusts and other organisations who want to join.

Q4 - What training have certification bodies received? How do you reduce variation in appraisal between different certification bodies?

All evaluators from the five certification bodies working in the Information Standard have received an overview of the scheme as well as the support materials available to scheme members. In addition, all evaluators have also been trained in Critical Appraisal Skills by the CASP team (a part of the Department of Public Health, Oxford University).

The United Kingdom Accreditation Service (UKAS) have accredited all five certification bodies to ensure consistency of approach. This is an audit of potential certification bodies, conducted by UKAS.

Q5 - What evidence exists to show that information providers will continue to subscribe to the scheme beyond the subsidy period?

We believe that organisations who join the scheme in the first three years will recognise the benefits of being a member of the Information Standard and will want to continue membership when the subsidy ceases. We will also be questioning the members of the scheme to measure their appetite for remaining members when the subsidy arrangement has ceased. The costs of re-evaluation are unknown at this time.

Q6 - How does the Information Standard tie in with the NHS Litigation Authority and Care Quality Commission requirements?

We agreed with the NHS Litigation Authority that certified members of the Information Standard will be deemed to satisfy the NHSLA’s requirements for producing patient information at Level 3. We will be working closely with the Care Quality Commission to reduce duplication where appropriate.

Q7 - How does this scheme link with similar plans from NHS Evidence?

The scheme from NHS Evidence is primarily clinical and non-clinical information aimed at a professional audience. It will provide a detailed assessment of the quality of processes used to develop systematically produced statements of best practice, such as guidelines. The scheme will initially apply to national bodies producing clinical and non-clinical recommendations, such as Royal Colleges and professional societies. It will be complementary to the Information Standard, and will ensure that patients, the public and professionals have access to information of the highest quality. Both will accredit sources of information, rather than individual products - however NHS Evidence will primarily target information for professionals while the Information Standard will primarily aim to reassure patients and the public.
Q8 - How will the Information Standard be marketed to the public?

We want to make sure the scheme delivers benefit and this means making sure that information users can recognise and understand the mark. We have a provisional plan to promote the scheme to the public in late spring 2010. Nearly all founder members now display the scheme logo on their websites and literature so the mark is beginning to be seen by the public. It is important to make sure that the timing of a public awareness campaign is right. If we promoted the scheme to the public before it is properly established, we could cause unnecessary confusion and anxiety.

Q9 - How will you be evaluating the scheme, both with information producers and with the public?

We want to make sure that both the public and member organisations reap the benefits of this scheme. We will be monitoring performance in both these aspects: through member feedback surveys and tracking the growing level of public awareness of the brand.

Q10 - What kind of support will be available to organisations applying to be certified (both financial and practical)?

Subsidies will be available to qualifying organisations based on their turnover: the subsidy does reduce after the first year of the scheme so organisations are encouraged to join soon. We have produced a number of support tools - online and face-to-face - including readiness checks on the website, workshops to prepare for certification as well as a dedicated Support Manager for information producers.

Q11 - This scheme is for England only - how does that fit in with what other countries are doing and how does it affect UK wide organisations?

As the scheme owner is the Department of Health we are, understandably, focussed on people in England. However, the scheme is open to any organisation that produces information that is useful to health and social care users in England. The idea of national boundaries in this context can be artificial, many organisations that join the scheme will be from other countries of the UK, and possibly even further afield. Given the digital age we live in, we cannot prevent the mark being displayed outside England and organisations based outside England are able to join the scheme.

We are also talking to the devolved authorities in the UK about the scheme as well as keeping abreast of initiatives outside the UK.

Q12 - Will the health information that NHS Choices, NHS Direct and the Department of Health produce also be going through the Information Standard certification process?

NHS Choices will be an early member of the scheme. We will be engaging with NHS Direct and other sectors in the Department of Health to encourage them to join the scheme.
Q13 - How will the Information Standard work with different formats like pictorial information and other languages?

Pictorial information and other languages can be certified as part of the Information Standard process - the only requirement is that it is scripted. Organisations wanting to join will need to agree the scope of their certification when they engage with a certification body: this can include formats in languages other than English.

Q14 - How will user-generated content be evaluated?

Currently, user-generated content is outside the remit of the Information Standard. However, we recognise that this is an increasingly important area that people use when searching for information on-line and we expect to expand the scheme to include this shortly.

Q15 - The 2006 report from the Picker Institute showed a ‘weak, non-significant relationship’ between the standards applied during the process of developing information and the quality of the end product, i.e. a good process did not necessarily equate to good materials. How does the Information Standard guarantee high quality materials and is there evidence to show a link?

There are a number of benefits that we are helping the Department of Health to monitor and one of those benefits is the link between applying the Standard and improving the quality of information products.
The future of the Information Standard

At the time of writing this guide it is still very early days for the Information Standard and it remains to be seen how widely it will be taken up by information producers, how it may impact ultimately on the quality of the information that is produced and what, if any, impact the scheme and the logo will have on patients and the public.

There are encouraging signs that the Standard may help information producers to create more effective and streamlined processes for producing information, and to raise the profile of quality information within their own organisations. Undergoing certification has helped to provide clear guidance for information staff and in some cases has helped information teams to gain a renewed sense of pride in their work.

However, there remain some key concerns particularly around the use of the Standard across the whole of the UK and its application to different information formats like pictorial and audio visual. As with any scheme that requires organisations to expend additional time and resources there have also been concerns about the costs of certification, particularly for small organisations. The Standard encompasses the social care arena as well as health but as yet there has been little testing in this area.

KP The biggest, and as yet unanswered question, remains the understanding and use of the Standard by the public.

Capita have plans in place to promote and establish the scheme. Their strategy aims to establish the scheme on a solid foundation post launch and create demand-led growth by running an ‘early adopter’ strategy, encouraging a small selected group of health information organisations to join the scheme. Capita will also engage organisations through a number of activities that explain and promote the new quality mark.

The scheme will be marketed to key audiences - information producers, health and social care professionals, and end users of the information (patients, service users, and members of the public) will all be targeted. Strategies used will include working with search engine providers and other information signposting organisations, focussed campaigns to stimulate awareness and a communications drive to inform consumer advisory bodies (such as Citizens Advice Bureau) about the quality mark and promote awareness.

As well as promoting the scheme as widely as possible Capita will also be developing services and resources to support information producers, both before and during the certification process. These include:

- the Information Standard website which will be the principal communications tool, providing information for the public as well as organisations seeking certification
- self-assessment tools to test readiness for certification
- a starter pack including a copy of the scheme and brand rules
- web-based tutorials and face-to-face training workshops
- a contact centre telephone helpline
- facilitating a network of information producers.
Perspectives on the Information Standard

Kate Llewelyn, Head of Information Services at Arthritis Care (Information Producer)

Becoming part of the new Information Standard was a priority for Arthritis Care. The amount of work involved in being part of the testing phase was considerable, but this should be more manageable for people coming on board now the scheme is finalised. Because we were part of the testing phase we had little guidance about what to expect as everyone was learning on the job - even the certification body. We were assigned our certification body (Royal Society of Public Health) and feel lucky to have ended up with them as they were as helpful as they could be during the long process.

The on-site assessment was very detailed and long. We were one of the witnessed visits by UKAS and the assessment took two full days. Mainly this involved three key members of staff, but also brought in other information team staff involved in the production of information.

Arthritis Care always had clear processes for producing health and lifestyle information - but those processes were not documented. We now have clear guidance, which the whole organisation has endorsed, which clearly sets us apart from some other organisations producing information.

Ensuring awareness of the rules of the scheme will be something the information team needs to address on a continuous basis. It is essential that colleagues throughout Arthritis Care understand the scope and the implications on information development for those items within it.

I feel the Standard is unnecessarily complicated in places - whether we can live to the letter of it will only emerge through using it in practice. It is worrying that this is an England initiative - most of the UK-wide charities involved in the testing phase would prefer it to be a UK-wide shared initiative and we are quite worried that the other nations will bring in contradictory schemes.

While I welcome the scheme, it will only be of value if the public is aware of it. The public needs to know what benefits the scheme brings to them. I do worry that the cost will prevent many organisations and charities taking part in the scheme in the future. The scheme must be meaningful and affordable to be successful.

Contact Kate: katel@arthritiscare.org.uk
Eve Laird, Director of Communications at Datapharm (Information Producer)

Datapharm’s experience of the Information Standard (IS) has been broadly positive. Our business exists to publish information about medicines and as such we already had in place processes and procedures to ensure the accuracy and currency of our information. Our reputation depends on producing high quality information. We have not, therefore, been required to set in place any new processes and procedures to achieve the standards for IS certification, although we have been required to produce more comprehensive documentation about the management of those processes and procedures.

SGS were nominated as our certification body. Our relationship with SGS has been excellent. The Datapharm team feels that the relationship has been extremely collaborative with both parties working together to help us achieve the required standards for certification.

Inevitably, as an organisation participating in the pilot we encountered challenges that are unlikely to be experienced by others in the future. For example, there has been a lack of clarity about ownership of elements of the scheme with involvement from the Department of Health, Capita, SGS and the Picker Institute.

Communication has also been poor, particularly around the timescales for awarding IS certification. It is frustrating that at the November 2009 launch of the IS none of the pilot organisations had been certified.

Whilst, as information producers the IS requirements have not been too onerous for us we do appreciate that for small organisations whose remit is wider than that of solely producing information, the scheme does have the potential to require a significant amount of resource. We have communicated our experiences and opinions to the Department of Health, who have noted the learning from the pilot.

Contact Eve: elaird@medicines.org.uk
Chapter Three:
Appraisal for information producers: individual resources

“Be careful about reading health books. You may die of a misprint.”
Mark Twain, Author, 1835-1910

Background
As well as appraising processes it is also possible to quality appraise individual pieces of information - whether that is a piece of printed information such as a booklet, leaflet, magazine or a website. Unlike the appraisal of processes this is an area where the information user can more easily get involved, by making use of tools designed to help them judge the quality of the information they read. As you will read later, this has its challenges.

There are hundreds of ways to evaluate individual pieces of health information, but there is no one tool able to assess all the components of every information resource. Commonly agreed quality criteria include currency, reliability, relevance, accuracy, authorship, design, layout and comprehensiveness. These categories also apply in the online environment as they do in print, though there are also additional quality criteria related to the online information such as interface functionality and usability.

The development of the Internet has been one of the main driving forces behind the development of appraisal tools. In fact there has been a huge increase in the number of tools and instruments available to assess website quality - from 58 to 270 in less than ten years.16

In 2002 the British Medical Journal devoted an issue to the subject of the Internet, exploring issues such as the quality of health information and the tools available to assess websites. Wilson’s article, How to find good and avoid the bad and the ugly, examined tools for rating the quality of health information and found a number of different approaches to doing so.17 She divided the approaches to assessing quality into five different categories (most of these can also be applied to printed information):

Codes of conduct - lists of recommendations for development and content, self-assessment by website providers.

Self applied codes of conduct or quality label - a quality logo is used to represent an organisation’s commitment to adhere to a code of conduct. An example is Health on the Net (HON).

User guidance systems - these allow users to assess quality against a set of standards. These are simple to implement but rely on the user to put them into practice. An example is DISCERN.

Filtering tools - these can be applied either automatically or manually and either accept or reject whole websites based on preset criteria. These provide a valuable shortcut for users.

Quality and accreditation labels awarded by third parties - these are quality marks awarded by a third party, usually for a fee, which show users that a website conforms to certain standards. It is the most advanced form of quality rating.

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17 Wilson P. How to find the good and avoid the bad and the ugly: a short guide to tools for rating quality of health information on the internet. BMJ, 2002;324: 598-602
Wilson argues that tools, quality marks and codes of conduct are useful, but that ultimately they rely on consumers to use them appropriately.

Appraisal tools place the burden on the user - users need to have the time and motivation to find out what they mean and then apply them to the information they are reading. Arguably the greatest challenge is not the development of more tools, but helping and encouraging users of health information to see it critically.

If you do decide to use a formal appraisal tool to assess a piece of information there is a wide range available to you. There are formal tools and guidelines available to help producers evaluate quality, assess readability and accessibility, or guide the development of a resource. There are also a number of quality mark schemes, including Health on the Net. Some of the most commonly used and tested tools are included here.

**Tools for appraising printed information**

**DISCERN**

DISCERN is one of the most commonly used appraisal tools. It is a brief questionnaire that can be used by the authors of information on treatment choices, as a guide to the standard which users are entitled to expect. It also provides users with a valid and reliable way of assessing the quality of written information on treatment choices. Its uses are diverse and include:

- a screening tool for health information providers.
- a checklist for authors and producers of written consumer health information.
- a training tool for health professionals to improve communication and shared decision-making skills.

DISCERN consists of 15 key questions plus an overall quality rating. Each of the 15 key questions represents a separate quality criterion - an essential feature or standard that is an important part of good quality information on treatment choices.

Questions score between 1 and 5, with 1 indicating a resource does not meet the criteria, 3 indicating it partially meets it, and 5 indicating it fully meets the criteria.

[www.discern.org.uk](http://www.discern.org.uk)
Using DISCERN at Macmillan Cancer Support

Macmillan Cancer Support uses the DISCERN instrument to assess the quality of information about cancer treatment in booklets for people affected by cancer. In 1999 we developed the following scoring system in conjunction with the Centre for Health Information Quality.

We use this system in our ‘Directory of information materials for people affected by cancer’.

DISCERN scoring of leaflets and booklets on cancer treatment:

** Appraised and of good quality with some shortcomings
The publication rates fair to high (3 or above) on the majority of questions. A high overall quality rating indicates that the publication is ‘good’ quality with only some shortcomings; it is a useful and appropriate source of information about treatment choices.

*** Appraised and of fair quality with some shortcomings
The publication rated high and low on a similar number of questions, or the majority of questions rated in the mid-ranges (3). 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.

* Appraised and of poor quality with very serious shortcomings
The publication rated low (2 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.
Using DISCERN at Macmillan Cancer Support (continued)

Our experience has shown that DISCERN is a useful tool to assess the quality of information about treatment. We have done some limited testing of inter-observer variability and found that the two testers awarded documents very similar scores. Most producers have been happy with the score; often those that are not, take active steps to improve the quality of their information.

The main disadvantage of DISCERN is that it cannot be used to assess the scientific quality or accuracy of the evidence on which a publication is based. Nor can it be used to assess how accessible a publication is, for example to people with a visual impairment.

For more information about how Macmillan Cancer Support use the DISCERN instrument, contact Sue at shawkins@macmillan.org.uk

Evaluation of Quality Information for Patients (EQIP)

EQIP is a tool developed at Great Ormond Street Hospital to assess the quality of all types of written health information. A list of quality criteria was developed from the published literature on quality appraisal and these were then framed into questions. The resulting assessment tool was then validated over a number of years and published in a peer-reviewed journal in 2004. This link will take you to the research article: www.pifonline.org.uk
Information audit

A patient information audit can help to create a baseline from which to measure improvement in the quality of an organisation’s information. This should be the first task of any newly appointed patient information manager. At its most basic level, it can provide a list of what information is being used throughout the organisation and by which departments. This is essential for rooting out duplication. As an example, the first information audit at Great Ormond Street Children’s Hospital showed that there were upwards of 20 different maps being sent out to patients and families.

Audit at GOSH started in the mid 1990s, with the appointment of both a patient information manager and a publications manager. A baseline audit enabled us to understand what information was being used and by whom. This gave us a place to start and helped us plan our forthcoming work.

In the years that followed, the audit became a way of assessing the quality of information being produced as well as locating it. For the first few audits, the DISCERN tool was used, but this proved to be less well suited to audit than planned, so the EQIP tool was developed.

The patient information audit is now a regular event at GOSH, with additional spot checks as required. The audit enables us to identify ‘loose cannons’ - those who are not producing information following our guidelines - and makes it easier to produce an annual action plan of information requiring review, either due to poor quality or because it is out of date.

The process has changed over the years too. At the start, everyone sat in a room and audited the material using printed forms. Today, we have an electronic form that allows auditors to review materials at their convenience within a set time period.

An important change in 2009 was the inclusion of non-GOSH produced material in the audit, as required by the NHS Litigation Authority. While we will not be able to change any non-GOSH produced material, the audit result will inform the decision whether to recommend their use or not.

There are several points to consider when planning an audit:

- Which assessment tool will you be using?
- Who will form the audit team?
- How will you collect the information to be audited?
- How will you communicate the results of the audit?
- How will you use the audit results?
At GOSH, the audit team is formed from members of the Child and Family Information Group, a multidisciplinary group of clinicians and non-clinicians. A short teaching session ensures that the audit team is familiar with the assessment tool and several pieces of written information are assessed as a group to confirm that each member is assessing the information in the same way.

The information is collected both by submission from clinical staff and as part of a ‘walk round’ of all the wards and departments. Each piece of information is logged into a spreadsheet with details of publication year, author and format. Once the teaching session has taken place, the information is distributed to the audit team, making sure that no one is auditing their own work.

Once the audit has taken place, the results are sent back to the audit leader who calculates the score achieved by each piece of information. Because the EQIP tool scores are linked to actions, these results form the basis of the action plan for the coming year. These results are then published in general terms and individual results communicated to authors or clinical experts, with the expectation that amendments be carried out in a timely manner. This is also an ideal opportunity to identify materials requiring updating during the coming year - we specify that information should be reviewed and updated as necessary every four years. Authors have three months to let the information manager have a plan for amendment. The final updated version is expected within six months otherwise the information is withdrawn.

Although a patient information audit is a lengthy task, it has proved invaluable at GOSH. Despite having strict guidelines for producing information, there are still some clinicians producing information without reference to the guidelines. It helps identify areas where further teaching on producing information is required and identifies potential for duplication of information.

The annual audit at GOSH is a vital project that forms the basis of the Child and Family Information Group’s work. In fact the process works so well that it is currently being rolled out to cover integrated care pathways at GOSH.

Contact Beki at: MoultB@gosh.nhs.uk

Great Ormond Street Hospital for Children NHS Trust

NHS Trust
Tools for websites

“Information on the Internet is subject to the same rules and regulations as conversation at a bar.”

Dr George Lundberg, Physician, former editor of Medscape

The Internet is different from most other information sources because it is not quality controlled. Anyone can publish on the web - there is no-one quality checking or assessing information. The Internet’s growing popularity as a source of health information, accompanied by the lack of regulation of websites, has resulted in the development and testing of tools to evaluate the quality of health information websites. However, only a few studies have tested the validity and reliability of these tools.

Web accessibility evaluation tools can significantly reduce the time and effort required to carry out evaluations.

Bobby

This was a web accessibility software tool from the United States designed to help expose and repair obvious barriers to accessibility and encourage compliance with accessibility guidelines. It offered prioritised suggestions based on the Web Content Accessibility Guidelines provided by the W3C Web Access Initiative. Bobby allowed developers to test web pages and generate summary reports highlighting critical accessibility issues before posting content to live servers. The program is now part of IBM’s Rational Policy Tester Accessibility Tool.

LIDA tool

Developed by UK evidence based web company, Minervation, to help web designers and information staff evaluate the accessibility, usability and reliability of healthcare websites. The tool covers both design and content.

www.minervation.com

WC3: The Web Accessibility Initiative

The Web Accessibility Initiative works with world-wide organisations to develop strategies, guidelines and resources to help make the web accessible to people with disabilities. They list a number of tools that can be used to assess the accessibility of websites.

www.w3.org

Quality marks

Both of the quality marks listed below are awarded to health websites by a third party. The presence of a quality mark aims to show users that the site conforms to certain standards.

Health on the Net (HON) Code of Conduct for medical and health websites

HON was created by Health on the Net Foundation to improve the quality of information for both patients and medical professionals.
Their Code of Conduct for medical and health websites addresses the reliability and credibility of information. All certificated sites meet the eight key principles within the Health on the Net code. Certification is free of charge.

The certification conducted by HON implies a thorough evaluation of websites according to their guidelines. There is a continuous surveillance over the year and a systematic annual review of HON certified websites.

The HON Code of Conduct is not an award system and it does not rate the quality of the information provided by a website. It defines a set of rules to:

• hold website developers to basic ethical standards in the presentation of information.
• help make sure readers always know the source and the purpose of the data they are reading.

While primarily intended for healthcare site developers and publishers, the blue-and-red HONcode seal on subscribing sites also helps users identify sources of reliable information.

Organisations apply by completing and submitting a questionnaire. If the site passes review, permission for using the HONcode seal will be given. 

www.hon.ch

**URAC**

URAC, is an independent, non-profit organisation based in the United States (US) that promotes healthcare quality through its accreditation and certification programs. URAC offers a wide range of quality benchmarking programs and services, including one on consumer education and support. URAC accredits many types of healthcare organisations including hospitals and health websites. Only four US organisations have achieved accreditation for consumer education and support. 

[www.urac.org/programs](http://www.urac.org/programs)

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**Guidelines for developing high quality information**

Although these are not formal appraisal tools they do provide good practice guidelines that information producers can use. The guidelines below include those that can be applied to any general health information publication, those that inform the development of NHS information resources (but which can be used more widely) and those that can help you to produce accessible information.

**British Medical Association (BMA) appraisal process**

The process and criteria for printed materials and websites entered into the BMA Patient Information Awards provides a useful checklist for the production of information materials. There are different appraisal processes for printed and electronic materials. Each resource is individually evaluated using appraisal criteria developed specifically for the award. A panel of experts meet to discuss these appraisals and to select a shortlist of titles for consideration by the final judging panel.
There is a set of core criteria which all shortlisted entries must achieve.

Printed resources must have:
• a date of publication
• service user and health professional involvement in the production
• a clearly stated target readership and content that is appropriate to this readership
• accurate clinical information
• no spelling or grammatical mistakes.

Websites must have:
• the name and status of the author(s) clearly stated
• service user and health professional involvement in the production
• constantly checks and updating.

www.bma.org.uk

The King’s Fund Guide

Producing Patient Information - How to research, develop and produce effective information resources

This guide is designed to support a wide range of health professionals in the public, commercial and voluntary sectors to develop the quality and impact of the information they produce. With a foreword by Harry Cayton, the then National Director for Patients and Public, Department of Health, this edition has information about new media and the Internet. The guide also shows how to use traditional media, such as print, to the best advantage. This is an updated reprint of the second edition of this guide, originally published in March 2003.

www.kingsfund.org.uk

NHS Patient Information Toolkit

These guidelines are for NHS organisations developing written information for patients and the public. It is recommended that all NHS organisations follow these guidelines. The resources include guidance on how to produce written information for patients, planning and delivery, presentation and communicating with different audiences, plus a series of checklists and templates. The guidelines were developed in partnership with the Patient Information Forum, the Royal National Institute for Blind People and the Plain English Campaign. The NHS Identity website, where the toolkit is hosted, also contains other useful guidance such as:
• producing posters
• how to write a print specification
• checking that your communication complies with the NHS guidelines in the NHS Identity checklist
• tips for producing better letters.

www.nhsidentity.nhs.uk
NHS Toolkit: Providing patients with better information in emergency departments
This toolkit offers practical support and guidance to help staff improve the information provided for patients in the emergency department. It is intended for anyone involved in providing information to patients, or in making decisions about how a Trust communicates with them. The suggestions and ideas offered in the toolkit are supported by case studies and networking contacts, as well as links to other useful documents and resources on the web. There are guidelines on signage, leaflets, information screens and video. There is also guidance on providing information for people whose first language is not English.

www.dh.gov.uk

Royal National Institute for Blind People (RNIB) Web Access Centre
The RNIB Web Access Centre pages offer information and advice on making websites accessible to everyone. The Access Centre provides news and case studies about building accessible websites for people with visual impairment. There are ideas on how to make your website work for people with sight problems, hearing, mobility and cognitive impairments. An added benefit is that most of the advice will help people using older browsers, slow dial-up or satellite connections, as well as newer technologies such as mobiles and Personal Digital Assistants (PDAs). RNIB also provides technical, design and editorial guidance, plus information on testing, standards, articles and links to useful resources.

www.rnib.org.uk

Scottish Accessible Information Forum (SAIF) Guidelines
The Scottish Accessible Information Forum (SAIF) aims to make information more accessible, enabling disabled people and carers to access timely and accurate information about a wide range of services. SAIF produces quality standards in information provision for disabled people and carers.

www.saifscotland.org.uk

Readability tools
Readability refers to how easily the target audience for a text can read and understand it. There are a number of tools that can help you to appraise written text for readability by applying a standard formula to selected text. All readability tools rely on a very rough gauge of the level of reading people have acquired by a certain point in their development. But successful reading is about far more than word recognition - it is about other factors such as style, physical presentation, learner interest, confidence and skill.

Readability tools are a subject of debate in the world of plain English - some people view them as a useful starting point when assessing the clarity of information, others as a tool to encourage poor writing.

As a rule, readability formulae can be useful tools, but should only be used as a guide because they do have limitations. They can be helpful in analysing what you have already written and are also good for comparing several different documents, or different versions of the same document.
However, readability tools only look at language, they do not take into account the tone of the information, the structure or layout and design. They measure text crudely and you will get the same score whether a sentence is written backwards or forwards. There is also no guarantee that a short sentence will be understandable. Getting feedback from your users, using good practice guidelines and your skills as an information producer will be more useful and reliable than relying on readability formulae.

Applying different readability tools to the same piece of text will also give you different scores and different reading levels. Cutts, in his article *Writing by numbers: are readability formulas to clarity what karaoke is to song?* argues that there is a huge difference between Flesch-Kincaid and SMOG - this may be because SMOG wants a 100% comprehension level, where as Flesch-Kincaid only 75-80%. The results of testing therefore depend significantly on which tool is used.

These are some of the most commonly used readability tools.

**Text editing software**

Text editing software is a way of checking text. Sophisticated programmes, such as Stylewriter, check documents for style and English usage faults and encourage clear writing. General word processing packages also contain grammar checkers which can assess text for possible errors in grammar and suggest alternatives. However, some of these do contain software flaws, so ideally you should use specialist readability software.

**Flesch-Kincaid Index**

The Flesch-Kincaid Grade Level, originally developed in the 1940s but revised during the 1970s, is the most well-known and commonly used readability formula. It is available on Microsoft Word as a grammar tool, but should be used with caution or not at all, as it may give you inaccurate readings.

Flesch-Kincaid displays the readability of a document as an American grade-level (year of school); you can convert the American grade level to the British reading age by adding five to the final readability score. This is what the software does:

- works out the average sentence length by dividing the number of words by the number of sentences
- works out the average number of syllables per word by dividing the number of syllables by the number of words
- applies the following formula to arrive at the American grade level (Average sentence length x 0.39) + (average number of syllables per word x 11.8) - 15.59.

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18 Cutts M, *Writing by numbers: are readability formulas to clarity what karaoke is to song?* Plain Language Commission, Edition 4. 2008. www.clearest.co.uk
Word processing software, such as Microsoft Word, also has a second readability score - the Flesch Reading Ease score. This gives a score from 0 to 100 (with higher scores representing greater reading ease), rather than a grade level score. See Table 1 for information about reading ease scores and equivalent reading ages.

**Table 1: How the Flesch Reading Ease score equates to British reading age**

<table>
<thead>
<tr>
<th>Flesch Reading Ease score</th>
<th>British reading age (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>90-100</td>
<td>10</td>
</tr>
<tr>
<td>80-90</td>
<td>11</td>
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<td>70-80</td>
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<td>60-70</td>
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<td>30-50</td>
<td>18-21</td>
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<tr>
<td>0-30</td>
<td>College graduate</td>
</tr>
</tbody>
</table>

**Sue Hawkins, Information Materials Researcher, Macmillan Cancer Support**

**Using the Flesch readability score at Macmillan Cancer Support**

Macmillan Cancer Support uses the Flesch readability score to test the readability of all booklets and leaflets included in the ‘Directory of information materials for people affected by cancer’.

We chose the Flesch readability score because it is well known and can be run on many word processing packages, for example by using the Spelling and Grammar function in Microsoft Word. The score calculates readability based on the average numbers of syllables per sentence. Scores range from zero to 100.

- **0-30** Very difficult (scientific paper)
- **30-50** Difficult (academic paper)
- **50-60** Fairly difficult (quality newspaper)
- **60-70** Standard (digests)
- **70-80** Fairly easy (slick fiction)
- **80-90** Easy (pulp fiction)
- **90-100** Very easy (comics)

Standard writing averages approximately 60 to 70. The higher the score, the greater the number of people who can easily read the document.

We take three samples, each of 100 words, from the beginning, middle and end of the text. The disadvantage of this approach is that booklets and leaflets vary enormously in length and 300 words is often not representative of the whole document.

The text at the beginning and end may be quite general with few technical or medical words. It has also been time consuming in the past when many materials were not available electronically.

We are now using some free software to test the whole document, whether it is available as a Microsoft Word document or as a PDF. This will reflect more accurately the overall readability of the document and is also much quicker than cutting and pasting text into Word. Information about treatment options often necessarily uses complex words and although these may be explained clearly in the text or glossary, this may decrease the Flesch readability score.
Using the Flesch readability score at Macmillan Cancer Support (continued)

The majority of items assessed for the most recent edition of the Directory scored from 50-60 (‘fairly difficult - quality newspaper’ - see Table 2 opposite). We advise that the Flesch scores given in the Directory of Information Materials are used as a relative score rather than an absolute indicator i.e. they should be used to compare the readability of resources on a similar topic.

For more information about how Macmillan Cancer Support used the Flesch readability score, contact Sue at shawkins@macmillan.org.uk

WE ARE Macmillan. Cancer Support
Fry Formula
This is a method of determining readability by hand and derives a reading grade level from calculations and reference to a chart. Reading difficulty level is calculated by the average number of sentences and syllables per hundred words.

These averages are plotted onto a specific graph; the intersection of the average number of sentences and the average number of syllables determines the reading level of the content.

To calculate a grade-level score:
1. Randomly select three separate 100 word passages (count every word including proper nouns and numerals).
2. Count the number of sentences in each 100 word sample
3. Count the number of syllables in each 100 word sample
4. Plot the average sentence length and the average number of syllables on the graph
5. The area in which it falls is the approximate grade
Gunning FOG Index

This is a method for analysing written materials either by computer or by hand. The test works on the basis that shorter, well-written sentences achieve a better score than long sentences in complicated language.

www.readabilityformulas.com

Sarah Carr, Carr Consultancy

How to work out the Gunning FOG Index for your text

1. Take a passage of around 100 words from your text. This should consist only of complete sentences - so don’t worry if the sample has slightly more or fewer than 100 words.

2. Work out the average sentence length by dividing the number of words by the number of sentences.

3. Count the number of words with three or more syllables, but excluding:
   - words that start with capital letters
   - words that are over three syllables because they have had ‘-ing’, ‘-ed’ or ‘-es’ added on the end.
   - words that combine two easy words, for example ‘anti-smoking’ and ‘photocopy’.

This gives you the percentage of hard words.

4. Add together the average sentence length and the number of hard words, and multiply the total by 0.4. The result is the lowest American grade level that could easily read the text.


For more information contact Sarah at: sarahcarr@carrconsultancy.co.uk
SMOG
(Simplified Measure Of Gobbledygook)
This was introduced by McLaughlin in 1969 and predicts 90-100% comprehension. It is often used to analyse health and medical texts. To get an accurate SMOG level for a long piece of text, most methods recommend taking at least three samples - for example, one each from the beginning, middle and end - and taking the average of the three scores.

The National Institute of Adult Continuing Education has made a calculator available via its website at www.niace.org.uk which can be used to calculate the readability level of any text that is pasted into it.

Calculating the SMOG level of a text
1. Select a page of a book
2. Count 10 sentences
3. Count the number of words which have three or more syllables
4. Multiply this by 3
5. Circle the number closest to your answer
   1 4 9 16 25 36 49 64 81 100 121 144 169
6. Find the square root of the number you circled
   1 2 3 4 5 6 7 8 9 10 11 12 13
7. Add 8 = Readability level

Most people will understand a readability level under about 10.

Analysis undertaken by the National Institute of Adult Continuing Education has shown average scores for newspaper editorials as follows:

The Sun: under 14

The Daily Express: under 16

The Telegraph and The Guardian: over 17

Taken from National Literary Trust website:
www.literacytrust.org.uk
The down-side of readability tools

Readability tools are often criticised for not predicting the true reading ease of a piece of text, and there are a number of things that they cannot tell you, such as whether:

- the content is good - whether it is accurate, for example
- the text is logically arranged and easy to navigate
- grammar and punctuation are correct
- the text includes personal reference words, like you and we, which make it accessible
- the presentation is appealing.

Most importantly text may score well when put through a readability tool, but it can still be meaningless, inaccurate or misleading. Although there is evidence to show that most people understand more when words and sentences are short and simple, it is also true that long words and sentences are not always difficult to understand and short words and sentences are not always easy to understand.

In essence readability tools should be used with caution, and then only as one of the methods used to assess information for quality, readability and accessibility.

To find out more about readability tools and their limitations, and the use of other methods to test readability, read Writing by numbers: are readability formulas to clarity what karaoke is to song? by Martin Cutts at the Plain Language Commission.

www.clearest.co.uk

There are a number of organisations that can assess your publications for clearly written understandable English, which includes design and layout. The two main ones in the UK are the Plain English Campaign and Plain Language Commission. Contact details are in the useful organisations section.

More information and the formulas themselves can be found on Wikipedia:

www.wikipedia.org
Award schemes for information resources

Although not technically appraisal tools or formulae, awards that recognise the quality of consumer health information and communication with patients and the public are worth exploring. The British Medical Association (BMA) Patient Information Award is the longest running and attracts a growing list of applicants each year. The criteria for judging are publicly available, which means that they can be used as guidelines for developing resources (see earlier section) as well as providing public recognition of a quality piece of health information.

All of the awards listed below are given annually and provide an opportunity for you to showcase your work.

**BMA Patient Information Award**

The BMA's Patient Information Award was first given in 1997 to recognise quality in written patient information leaflets and small booklets. The aim of the award is to ‘encourage the production and dissemination of accessible, well-designed and clinically balanced materials which will enhance patients’ understanding of health issues and their ability to participate in decisions about their care’.

The awards cover both printed leaflets/booklets and websites. Special awards are made each year for materials aimed at carers, men’s health, women’s health, learning disabled people and young people.

The criteria for assessment have evolved over time. They focus on areas such as evidence base, authorship, accessibility, user involvement and use of language, which contribute toward information of high quality.

**Bupa Foundation Communication Awards**

The Bupa Foundation Communication Awards are made annually in recognition of excellence in medical research and healthcare in seven categories. The category of relevance to those who produce health information is that of communication. The Communication Award is given for effective communication between healthcare professionals and patients. The award is run in association with the Patient Information Forum.

Applicants must demonstrate:

- Enhanced mutual understanding between patients and healthcare professionals, and should describe work which could be widely adopted for the benefit of patients.
- Tangible evidence of improvement in communication, for example, through case studies.

Each award is £15,000. This is divided into two parts: £5,000 is paid direct to the individual or team members and £10,000 is used to further the award winner’s project.

**Communiqué Awards**

The Communiqué Awards recognise and reward excellence in PR and medical education in healthcare. There are more than 20 categories, including awards for writing excellence, and best patient and public campaign.

www.pmgrouplive.com
Ask about Medicines Awards
The Ask about Medicines Awards for Excellence were launched in 2006 and were designed to recognise excellence in:
• increasing people’s understanding about medicines and medicine taking
• helping medicine users to be involved in decisions about their treatment
• achieving better communication between people and their healthcare professionals.

Developed in partnership with the Association of the British Pharmaceutical Industry (ABPI), hundreds of individuals and organisations involved in providing and delivering medicines information entered the awards over the three years the scheme was running (2006-8). There are plans to continue the awards scheme in the future.

www.askaboutmedicines.org

The Institute of Medical Illustrators Awards
The Institute of Medical Illustrators Awards are based on the recognition of excellence in clinical photography, graphic design and video. The awards comprise Gold, Silver and Bronze, as well as a Platinum awards (chosen from the Gold award winners).

www.imi.org.uk

The Association of Healthcare Communicators: Communicating Health Awards
The Association of Healthcare Communicator’s Communicating Health Awards recognise excellence in all forms of communication in, and for, the NHS and health and social care throughout the UK. The awards acknowledge good practice, whether it is a campaign, newsletter or strategy. They are open to people working in or for the NHS and other health and social care organisations, including agencies and freelancers. Award categories include the Communicating Patient Safety Award, Best Website Award and Communicator of the Year Award.

www.assochealth.org.uk
Background

How and where people look for information about their health has changed dramatically over the past two decades. Although most patients get the information they need from face-to-face meetings with their health professional, there are also a range of other options for the individual who wants to know more. That person can go online and read websites and blogs, visit online communities and virtual worlds, listen to podcasts and contribute to social networking sites.

If information users are to judge for themselves whether information is of a high quality then they will need the right skills to do so. This is likely to mean having a relatively high level of health literacy and some critical appraisal skills. However, in England more than half of the adult population has literacy skills below the level needed to discuss their condition in an interactive way with their doctor.\(^\text{19}\) In Scotland it is thought that as many as 800,000 adults have low literacy and numeracy skills and could benefit from literacy support - levels in Wales and Northern Ireland are thought to be similar.\(^\text{20}\) Low health literacy levels are also likely to be more prevalent among ethnic minorities, older people, lower socio-economic groups and those with long-term health problems and disability.\(^\text{21}\)

Health literacy is not just about reading, writing and numeracy ability or applying literacy skills to a healthcare setting. Health has its own specific language, environment and processes so an understanding of everyday information is not necessarily enough to enable an individual to make sense of their health needs, treatments and choices. It is important to also remember that even literate people may have trouble understanding or interpreting some aspects of modern healthcare.

Critical appraisal is the process of assessing and interpreting the evidence behind a statement or piece of information and judging how valid it is.

Although many people who work in the healthcare environment have the skills necessary to decide whether the information in a health news story, booklet or article is likely to be accurate or not, the likelihood that the majority of the public will be able to is small.

Risk and Dzenowagis conducted research for the World Health Organisation in 2001 examining quality initiatives and online information.\(^\text{22}\) The authors felt that one of the most challenging problems to address was the 'burden placed on the citizen'.

Information users need a high level of understanding of both the Internet and the health information they seek in order to make use of quality initiatives. Users must want to have interest in a site’s seal of approval or accreditation. In addition, the shift towards patient choice and the increasing involvement of individuals in their healthcare has led to a gap between the demands placed on the individual and their capacity to be able to help themselves - to have the skills and experience to do so.


Some are questioning whether we need quality tools at all and whether information users might more usefully find their own way of informally assessing information. In the editorial piece Quality of websites: kitemarking the west wind (2000)\textsuperscript{23}, Delamoth argues that some forms of media cope well without kitemarking and that consumers learn to judge what is quality based on how something looks, where it is sold and how it is promoted. Consumers also develop a loyalty to brands over time, visiting the same organisations or companies again and again because they offer a reliable product. This is increasingly true of health information websites with a few trusted brands attracting the majority of health information seekers. Perhaps we should rely on information users to be the ultimate judge of what constitutes quality and rely on market forces to sift the wheat from the chaff?

Deshpande and Jadad argue that it is the users of health information that should be leading the way in the search for quality.\textsuperscript{24} They suggest that users could judge quality - by providing ratings or recommendations on health information - based on their experiences of using it. Collective ratings from a large number of individuals could therefore help to identify the good and worthwhile information, from the not so good or so useful. Current non-healthcare examples of this type of scoring system are Amazon and Trip Advisor’s five star rating scheme, where members of the public assess the quality and usefulness of a product or service. Perhaps in the future, this is what the accreditation of health information will look like.

Searching the Internet

“Experts say that Internet users should check a health site’s sponsor, check the date of the information, set aside ample time for a health search, and visit four to six sites. In reality, most health seekers go online without a definite research plan.

The typical health seeker starts at a search site, not a medical site, and visits two to five sites during an average visit. She spends at least thirty minutes on a search. She feels reassured by advice that matches what she already knew about a condition and by statements that are repeated at more than one site. She is likely to turn away from sites that seem to be selling something or don’t clearly identify the source of the information.

And about one third of health seekers who find relevant information online bring it to their doctor for a final quality check.”

Vital decisions, Pew Internet & American Life Project, 2002

\textbf{www.pewinternet.org}

\textsuperscript{23} Delamoth T. Quality of websites: kitemarking the west wind. BMJ 2000;321:843-844

\textsuperscript{24} Deshpande A, Jadad A. Trying to Measure the Quality of Health Information on the Internet. Is it time to move on? The Journal of Rheumatology 2009;36:1: doi:10.3899/jrheum.081101
Currently, Internet search engines, such as Google, Yahoo and Bing, are one of the most important tools for any information seeker. The disorganised and vast resources of the Internet can be easily and quickly accessed and sorted. It is often assumed that the most relevant and necessary links are displayed on the first page of results. However, this is very often not the case and it is therefore vital that information users are able to critically appraise the information they see.

A US report published by Consumer WebWatch and Stanford University in 2002 found that people rarely used rigorous criteria when evaluating credibility - what people say they do and what they actually do are very different. The data showed that the average consumer paid far more attention to the superficial aspects of a site than to its content. For example, 40% of consumers in the study assessed the credibility of health sites based in part on the appeal of the overall visual design of a site. Secondary factors were those attributed to credibility in health information websites - comprehensiveness, clarity and potential bias.

The Pew Internet & American Life Project study Online Health Search 2006 found that most Internet users start using a general search engine when researching health information online. Just 15% of health seekers say they ‘always’ check the source and date of the health information they find online, while another 10% say they do so ‘most of the time’. In 2009 Ofcom, the regulator and competition authority for the UK communications industries, published the results of research into how people assess online content and services. The main purpose of the research was to examine how people assess the trustworthiness, independence and balance of online content. These are some of the main findings:

- Whether participants were evaluating a site in terms of either its safety or reliability, they were influenced by a range of factors including the amount of Internet experience they have, their confidence online, their overall life experiences and their cognitive skills.

- In relation to assessing the trustworthiness of online content, this study found that a perception of familiarity was the most important factor - consciously recognising cues (such as a known company name or logo) and a swift, intuitive judgement.

- The study demonstrated how first impressions are not necessarily the end of the process. The initial intuitive responses may be followed by a more conscious evaluative process. This process incorporated a range of factors such as reading the site for signs such as geographic contact details, evaluating the look and feel of a site, or checking to see if the information is up-to-date. Other factors included ease of navigation and reputation.

- Many participants drew on offline reputation or word-of-mouth recommendations from friends or family when deciding which sites to use and trust. Only a small proportion of participants said that they undertook detailed research or cross-checking against other sources.

27 Duckfoot Research. How people assess online content and services, Ofcom. 2009. www.ofcom.org.uk
There is a wide range of tools available for information users to apply to the information they read, be that a website or a printed publication.

Many voluntary organisations, NHS Trusts and Health Boards and library services produce their own set of criteria for information users. For example, Health Information Week is a campaign run throughout the West Midlands to improve access to health information and includes leaflets and sessions to show the public how to use a computer to find good quality health information. The British Medical Association also publishes a guide to finding reliable health information on the Internet (www.bma.org.uk). Quality is not a UK only issue, for example, the Australian Government has a list of criteria on its Healthinsite website called How to Assess Health Information Online: www.healthinsite.gov.au

**Wendy Marchant, Macmillan Cancer Information Service Manager, West Suffolk Hospital NHS Trust**

Evaluating cancer information (health information) aimed at patients, family and friends.

In October 2006 I worked in the Norwich Cancer Information Centre and started the Macmillan supported ‘Health Information Services Management’ course, a double MSc module, at University of Central England in Birmingham. One of my assignments was evaluating health information. During lectures we went through all the things we would need to do to make sure that the information we provide to users is right for them. Whilst undergoing this part of the course I realised that as a profession we are very good at training staff to evaluate how good a piece of information is, but not very good at helping the public to do the same.

With doctors frequently complaining that patients come into clinic clutching Internet print outs, books, leaflets and news articles which are not relevant to their treatment or care, I thought that there was a gap in information provision to help people decide for themselves whether or not some information really applies to them. From this I decided to write a leaflet which could relate to general health or be adapted to a specific group of patients (such as cancer). It aims to help people evaluate what they find for themselves (from the Internet, in the library, in the media or anywhere else).

**Developing the leaflet**

I talked to some of the hospital’s health professionals to get a feel for the sort of mistakes patients were making when bringing information in. I listed them and matched them with the notes I had taken on my course and wrote an initial draft. Issues included:

- looking at who the information is for - giving unsolicited information to others, adult, child, patient, carer, etc
- asking if people were looking at symptoms which may or may not have been diagnosed
Chapter Four: 
Appraisal for information users

Developing the leaflet (continued)

- being specific about exact diagnosis (some conditions are similar but not the same)
- checking dates to see how old the information is (review dates present)
- who wrote the information (patient, professional, someone selling something, drug company, media) to see what their credentials are (some scepticism needed here)
- what format (audio, written, large print, DVD, etc)
- culturally/user sensitive, e.g. visually impaired, learning disability, Black and Minority Ethnic communities
- country of origin (UK, USA, Canada, Australia or elsewhere)
- target audience for the information - technical paper aimed at doctors and researchers or patient factsheet
- useful links and websites - where to get good patient information

Next I sent a draft to some more professionals for their views on what I had written and made amendments accordingly. Secondly I gave a draft copy to patients and information centre users with an evaluation form to return to see if they found it useful and see if they had any comments or amendments. I sent the final draft to the hospital's patient information lead to be checked by the patient panel.

It was approved and is now in use in the West Suffolk Hospital. There has been interest from other hospitals and I think there are some who have used and adapted it to their own region. I entered the leaflet into the NHS Health Enterprise East Awards 2007 (service delivery category) where it did not win the award but was given a commendation.

Some patients are coming across the leaflet and finding it helpful. Some doctors and other professionals are gradually discovering it too and find it could help to cut down the number of discussions where people have thought that some information they have found might help, when it was actually irrelevant. In the longer term, hopefully it will help to reduce the number of people who have their hopes raised by finding some information when it is really not applicable to them.

For a copy of the leaflet, contact Wendy at:
wendy.marchant@wsh.nhs.uk

WE ARE MACMILLAN CANCER SUPPORT
Chapter Four: 
Appraisal for information users

Appraisal tools

Some of the main appraisal tools for information users are listed here, but there are many more.

DISCERN
DISCERN is a brief questionnaire which provides users with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem. It acts as an aide for consumers making decisions about treatment or who want to know more about a treatment they are using. Consumers, family, friends and carers can use DISCERN to assess the quality of written information and to increase involvement in decisions about treatment by raising issues to discuss with health professionals.

www.discard.org.uk

DISCERN Genetics
DISCERN Genetics is a questionnaire which helps people using information on genetic testing and screening to assess the quality of that information. DISCERN Genetics can also be a guide for authors and publishers of information on genetic screening and testing.

www.discern-genetics.org

International Patient Decision Aid Standards (IPDAS)
A checklist to help patients judge the quality of decision aids. Decision aids are tools that present benefits and risks in enough detail for patients to be able to use them in the decision making process. They are often tailored to the individual’s health status and help them to make specific choices about their treatment.

www.ipdas.ohri.ca

Judge
The Judge project was developed by Contact a Family and Northumbria University. They produced guidelines for judging the quality of health information websites for consumers and to assist support groups to produce good quality sites. The website is no longer publicly available but an archive version can be found at:

http://web.archive.org

Science Panel on Interactive Communication and Health (SciPICH)
This checklist of questions created by the SciPICH to help website users judge whether health information offered by a website or other e-communication is useful and reliable. The panel itself is no longer running but the checklist remains in the public domain.

www.health.gov
Health Literacy Group
This is a special interest group of the Society for Academic Primary Care, based at South Bank University in London. They are interested in building the evidence base for health literacy and its impact on people and their lives, and in supporting national policy to reduce inequalities. The group is committed to developing the evidence base for, and using that research to reduce the impact of, low health literacy on people’s health. The group has a website with more information, research and event details.
www.healthliteracy.org.uk

Health Rights Information Scotland (HRIS)
This is a project based in Consumer Focus Scotland (formerly Scottish Consumer Council) and funded by the Scottish Government Health Directorates. HRIS produce information for patients about their health rights, how to use NHS services, and what to expect from the NHS in Scotland. This information is provided to all NHS boards for use throughout the health service.

HRIS information is available in a number of translated and alternative formats (including easy read, audio and British Sign Language) from the HRIS website.
www.hris.org.uk

Information support roles framework (Scotland)
A 2009 study by Dr Pat Straw (Online Information Services for Patients and the Public - analysis of user needs; evaluation of current position; and recommendations for the future development in line with NHS 24) highlighted a number of issues about high quality information. Some of the key findings were:

- Significant numbers of people (1 in 5) would prefer doctors to give them any information they might need from the Internet, as opposed to finding it themselves, being helped to find it by doctors or other healthcare professionals, or being helped to find it, or being given it, by family and friends.
- The desperate need for online information to be constantly monitored and manually, as well as automatically, updated.
- The integration of NHS Education for Scotland and NHS Inform patient and public information should preserve:
  - A choice for users, in terms of the availability of information at different levels of complexity. All the surveys and focus groups highlighted how important having access to, and having clear lists of, different levels of information, from basic to detailed scientific/research, was to users.
  - An array, or library, of information on a particular topic from different sources.
  - A single gateway to health and social care information.

To read the report, go to the PiF website:
www.pifonline.org.uk

To support this report an Information Support Roles Framework has been drawn up. The framework from NHS Education for Scotland defines the generic information support skills that are an integral part of the day to day
work of healthcare staff at all levels, but are currently often unacknowledged and underdeveloped. The framework describes how healthcare staff in their information support role can use information literacy skills as part of a person-centred approach. www.knowledge.scot.nhs.uk

**Invest in Engagement website**

This website is a comprehensive review of the best worldwide evidence, in English, of what works to engage patients and the public in healthcare. The website aims to help healthcare commissioners and providers in England to deliver higher quality, more efficient care and treatment.

Created and developed by Picker Institute Europe, the site is a one-stop resource for everyone with an interest in patient and public engagement. This includes the policy context, regulation, the current situation, sources of help, and case study examples of engagement programmes being carried out now in England - some illustrated with video.

www.investinengagement.info

**Pew Internet & American Life Project**

The Pew Internet & American Life Project is one of seven projects that make up the Pew Research Center, a non-partisan, non-profit ‘fact tank’ that provides information on the issues, attitudes and trends shaping America and the world. The project produces reports exploring the impact of the Internet on families, communities, work and home, daily life, education, healthcare, and civic and political life. Reports include issues that relate to online health information.

www.pewinternet.org

**Picker Institute Europe**

Picker Institute Europe is a not-for-profit organisation that makes patients’ views count in healthcare. They build and use evidence to champion patient-centred care and work with patients, professionals and policy makers to strive for the highest standards of patient experience.

The Institute has produced a number of reports on consumer health information, exploring quality and accessibility and covering areas such as decision aids and information for people who have a condition that affects their appearance. They have also produced a report evaluating the information accreditation scheme testing phase.

www.pickereurope.org

**Plain English Campaign**

A business that fights against jargon and confusing language, while promoting crystal-clear language. The Plain English Campaign runs the Crystal Mark scheme which awards a logo to materials and websites that have been assessed and are written in ‘plain English.’

www.plainenglish.co.uk

**Plain Language Commission**

Managed by Martin Cutts, author of ‘The Oxford Guide to Plain English’, the business helps information producers use plain English principles to clarify their web and printed text. The business also provides accreditation of documents and websites with the Clear English Standard logo, writing-skills courses and document editing.

www.clearest.co.uk
Chapter Six: Appendix One: Policy Drivers

Over the past decade health policy in England has both reflected and led the move towards assessing the quality of health information using recognised schemes, quality markers, accreditation and appraisal. Policy makers in other countries of the UK have not yet chosen to develop a specific programme or commitments to an accreditation scheme for health information. However, there are also standards relating to the development and delivery of high quality information that are requirements for NHS organisations in other UK countries.

Scotland


This plan outlined the actions the Scottish Government wished to take to improve health. The central themes of the Action Plan are patient participation, improved healthcare access, and a focus on the twin challenges of improving Scotland’s public health and tackling health inequalities. Page 44 focused on information for patients stating that “much of this is well presented and of good quality, but it is not necessarily consistent or widely available, and may not, in all cases, meet quality standards or be written from a patient’s perspective” and suggested the following solutions:

- a consistent approach to produce high quality patient information across NHS Scotland.
- information partnerships with key national voluntary organisations to maximise the benefit to patients from the high quality, patient focused information they produce.

www.scotland.gov.uk

The Healthcare Quality Strategy for Scotland (Draft Strategy November 2009)

NHS Scotland has developed a draft strategy to create high quality, person-centred, clinically effective and safe healthcare services, and to be recognised as being world-leading in its approach. The draft proposes a number of strategies which relate to consumer health information, a patient-centric approach and quality. The report authors propose that Scotland generally has well-recognised standards of healthcare quality in specific areas, but there are important challenges in relation to person-centredness, and in learning from and rolling out the individual areas of high quality services. Specific proposals include:

‘A step change in health literacy across the whole population, taking full advantage of existing and new approaches to communications, technology and resources to ensure that everybody has access to the information and advice they need, when they need it to support them in maintaining health, managing ill health and in making shared decisions.’

www.scotland.gov.uk

The Patient Rights (Scotland) Bill

The Bill states that it is the right of every patient that the healthcare they receive is patient-focused, which means that the provision of healthcare takes into account the patient’s needs.
Chapter Six: Appendix One: Policy Drivers

The Bill provides for the Common Services Agency of the NHS in Scotland to secure the provision of a patient advice and support service, and for there to be Patient Rights Officers. Healthcare is to:

- be patient focused: that is to say, anything done in relation to the patient must take into account the patient’s needs
- have regard to the importance of providing the optimum benefit to the patient’s health and wellbeing
- allow and encourage the patient to participate as fully as possible in decisions relating to the patient’s health and wellbeing
- have regard to the importance of providing such information and support as is necessary to enable the patient to participate.

www.scottish.parliament.uk

England


This set out how NHS staff would have the information they needed to provide and improve care, and how patients and carers would have the information necessary to make decisions about their own treatment and care. It contains the first mention of accreditation for sources of health information and also makes specific mention of the Centre for Health Information Quality, formed the previous year:

‘The development of a national gateway site to health information on the Internet will allow signposting of recognised sources of health information and will permit some accreditation of information sources’.

‘The role of the Centre for Health Information Quality will be strengthened to enable it to play a stronger role in accrediting patient and public information material produced by the NHS’.

www.dh.gov.uk

NHS Plan - A plan for investment, a plan for reform (2000)

The NHS Plan outlined the vision of a health service designed around the patient: a new delivery system for the NHS. It laid the blueprint for some now very familiar health information services and proposed an accreditation and kite-marking scheme for individual resources:

‘Patients will be helped to navigate the maze of health information through the development of NHS Direct Online, digital TV and NHS Direct information points in public places.’

‘NHSplus will kite-mark books, leaflets and other written material.’

www.dh.gov.uk
Chapter Six: Appendix One: Policy Drivers

Learning from Bristol: the report of the public inquiry into children’s heart surgery at the Bristol Royal Infirmary 1984-1995 (Kennedy Report 2001)
This report was produced following an independent inquiry into the deaths of children undergoing heart surgery at Bristol Royal Infirmary, and it made a major impact on the NHS. The report sets out a wide range of recommendations, including many that focus on information and communication.

Here are two that focus on accreditation:

‘The public should receive guidance on those sources of information about health and healthcare on the Internet which are reliable and of good quality: a kite-marking system should be developed.’

‘The NHS Modernisation Agency should make the improvement of the quality of information for patients a priority. In relation to the content and the dissemination of information for patients, the Agency should identify and promote good practice throughout the NHS. It should establish a system for accrediting materials intended to inform patients.’

www.bristol-inquiry.org.uk

Building on the Best: Choice, responsiveness and equity in the NHS (2003)
This report broadly set out how the Government intended to make NHS services more responsive to patients, by offering more choice across the spectrum of healthcare. Its main aim was to improve patient and user experience and build new partnerships between those who use health and social care services and those who work in them. The document states that the Government will:

‘Ensure people have the right information, at the right time, with the support they need to use it so that this becomes central to how we care for people - an information partnership which is no less than an information revolution. Working with a range of partners we will embrace new technology such as digital TV, develop a programme of ‘kite-marking’ information from a variety of sources so that patients know what to rely on.’

www.dh.gov.uk
Chapter Six: Appendix One: Policy Drivers

Better information, better choices, better health (2004)
This was a three year programme of action, at both national and local level. It aimed to improve access to high quality information that people need and want, to exercise choices about their personal health and healthcare. For the first time this document set out the development of a specific scheme for appraising health information - the Information Accreditation Scheme:

‘The Department and NHS Direct will build on this work and develop an accreditation scheme that meets the needs of both patients and health professionals, and is practical for information providers. As part of this, a set of information quality principles will be developed in partnership with the public, patients, carers and information providers. These will be used as criteria for accreditation, as well as for commissioning information and raising public awareness.’

Wales
Framework for Best Practice: The production and use of health information for the public (2002).
This framework is intended to provide guidance for those involved in the production and use of health information for the public in Wales. The framework is designed to encourage good practice amongst healthcare professionals and to facilitate future development in the field. Chapter 2 of the framework explores best practice in the development of health information, including user involvement, choosing format, developing content and ensuring accuracy. It includes elements such as:

• guidelines on the development and use of such information must be established amongst information providers in Wales
• evaluation should be integrated into the entire development process and will involve getting continual feedback from the target audience and intermediary users.

Northern Ireland
Quality Standards for Health and Social Care (2006)
This paper set out the standards that people can expect from Health and Personal Social Services (HPSS) in Northern Ireland. The standards are used by the Regulation and Quality Improvement Authority to assess the quality of care provided. These standards have five key quality themes, one of which is Effective Information and Communication. The standards that relate to consumer health information quality include those on involving patients, carers and the wider public, producing information that is subject to regular audit and review and using appropriate language and diversity in methods of communication.

www.dhsspsni.gov.uk

www.dh.gov.uk

www.wales.nhs.uk
The Centre for Health Information Quality (CHIQ) was established in 1997 by the Department of Health. The centre was a development agency, working to raise standards in health information for the public. Among other services, it offered appraisal and assessed leaflets, websites and information services.

CHIQ developed two sets of guidelines - for those producing health information and for those reviewing health information as well as a website called Hi Quality about health information quality. The centre also offered a forerunner of the Information Standard, a logo called the Triangle Mark. The Triangle Mark was designed to represent three quality themes - that information was accurate (up to date and evidence based), clearly communicated, and relevant (developed with consumers).

An article by Angela Coulter, then Director of Policy and Development at the King’s Fund, appeared in the British Medical Journal in 1999. In Informing Patients: An Assessment of the Quality of Patient Information Materials, the authors call on the then NHS Executive to adopt a number of proposals, among them to ‘Establish a system for accrediting patient information materials and websites to help patients and health professionals identify reliable information’. The article followed the launch of the King’s Fund’s publication of the same title, one of the first comprehensive looks at consumer health information and most crucially the user’s needs. The book explores the criteria for evaluating the quality of patient information materials.

In July 2000, the Department of Health’s (DH) NHS Plan raised the issue of quality marking information, followed one year later by The Kennedy Report, which recommended ‘establishing a system for accrediting patient information materials and websites to help patients and health professionals identify reliable information’.

NHS Direct then developed the NHS Information Partners programme - an accreditation process made up of eight quality standards. When organisations met steps one to four they could use the ‘NHS Approved’ information quality mark on their leaflets. On completion of all eight steps, they became full NHS Information Partners, and could carry the ‘NHS Information Partner’ quality mark on information materials. In addition, NHS Information Partners’ websites were promoted via links from relevant sections of NHS Direct Online. The key benefits of NHS Information Partner accreditation were claimed to be:

- NHS quality marking of websites and/or leaflets with a highly recognised, trusted brand
- website promotion via linking from NHS Direct Online, which then received over 500,000 visitors each month
- sharing experience with other organisations who produce health information
- ongoing support and future training opportunities.

Development work for the programme was undertaken in partnership with major cancer organisations, and it looked set to expand to allow a wide range of information producers to apply for Partnership status.

However, during the development process the need for a formal accreditation process became apparent and the programme as it was then came to an end.

NHS Direct and the Department of Health in England used the programme and the results of the development process to form the foundations of an information accreditation scheme. The development of the scheme took some time, and it was not until 2008 that a pilot testing phase got underway. Since the testing phase, the scheme has been rebranded and formally launched as The Information Standard. Full details of the scheme and the Standard are in Chapter Two.
Before The Information Standard officially launched it underwent testing with information producers and certifying bodies. 40 information producers took part in the pilot of what was then called the Information Accreditation Scheme. These were a mix of small, medium and large organisations from across the NHS, public, commercial and voluntary sectors. 36 of these organisations completed the pilot. The aims of the testing network were to:

- test the scheme Standard
- share their experiences in order to support the development of case studies
- help to develop the visual identity of the quality mark.

In addition to the information producers selected, five certification bodies were also chosen to apply the scheme Standard to all members of the testing network.

The Certification Bodies were:

- EMQC www.emqc.co.uk
- G4S www.g4sassessmentservices.com
- Knight International www.knightinternational.co.uk
- Royal Society of Public Health www.rsph.org.uk
- SGS www.uk.sgs.com

This pilot period allowed the certification bodies to become familiar with the scheme and to work with the information producers to finalise the process and the Standard and to develop the scheme rules.

Once the pilot was underway the Department of Health put out a tender to find an independent operator for the scheme. This was granted to Capita, who took on responsibility for the scheme as well as developing it into a self-sustaining business.

The Information Accreditation Scheme was renamed The Information Standard and a brand and a logo were created. In August 2009 the pilot ended and the final standard was published.

The Patient Information Forum held a workshop in June 2009 to discuss and explore The Information Standard, plus other methods of appraisal. Three perspectives of the scheme from the Information Standard pilot sites follow.
Case studies from the pilot sites

Dr Christopher Suter, Director of Certification, The Royal Society for Public Health (Certification Body)

The Royal Society for Public Health have been accrediting since the early 1990s. The organisation became involved with The Information Standard because it is seen as relevant to our mission and because it is also a business opportunity. We were invited to join a group of five (now four) other certification bodies taking part in The Information Standard. The Society sees the scheme as valuable because it can help the public to see the provenance of information and to distinguish between evidence and opinion. The time schedule for piloting the scheme was very tight for everyone. The certification bodies met together every six weeks to discuss the Standard, to agree how it should be interpreted and what type of evidence was acceptable for information producers to submit. The certification bodies worked with information producers to develop a set of rules for the scheme to help the process to run more smoothly.

The Society worked with eight of the information producers from the pilot group and found all of them to be highly motivated, willing to share experiences and mostly well prepared, although some organisations had a lot of work to do. There were lots of questions and, though the Certification Bodies are not allowed to offer specific help or advice about how to deal with or solve problems, they were able to provide useful, generic guidance to the information producers.

All of the Certification Bodies are themselves accredited by UKAS (The United Kingdom Accreditation Service - the sole national body recognised by government to accredit, against internationally agreed standards, organisations that provide certification services). This is central to the scheme because it allows information producers to be confident that the Certification Bodies can, and will, audit them effectively and fairly.

Potential challenges: The Information Standard logo has to be on the right pieces of information and it is up to information producers to ensure that this happens - the certification bodies cannot check all the information that an organisation produces, only sample it. The presence of the logo does not mean that a specific piece of information has been checked, only that the process by which it was developed was in compliance with The Information Standard. Not all information formats will be appropriate to be applied to the Standard.

Potential benefits: The scheme may have a wider impact than just allowing increased confidence in the information that carries the logo for the Standard. It should also encourage the public to begin thinking about the nature of evidence and how reliable any piece of information is.

Contact Dr Suter at: csuter@rsph.org.uk
Katrina Glaister, Trust Lead for Information, Salisbury NHS Foundation Trust (Information Producer)

Salisbury NHS Foundation Trust already had high standards for patient information and have had systems in place to produce quality information for the past ten years. There are also governance processes in place and the Trust had Level 2 NHSLA and met Standard C16 of the Annual Health Check. The Trust feels that it already produces high quality patient information.

So, why get involved in the Standard?
The information team sits within clinical governance at the Trust and they are passionate about patient information and driving up standards - they also wanted to be involved from the start. Balanced against that were some reasons why not to get involved - the Trust already has a good reputation for health information and is well respected, there are already a number of good systems in place to produce information of high quality. There is also a great logo in use already - that of the NHS logo which is trusted and recognised.

Challenges of meeting the Standard:

References - finding the evidence which demonstrates compliance with each of the elements within the Standard and encouraging clinicians to record the evidence used when writing information.

The difficulties of the Standard may alienate those clinicians who write information - for example the Trust has already worked very hard with clinicians to develop a robust and effective process for developing information, if they make it even more difficult and constrained than it already is then clinicians may ‘go underground’ and go back to producing their own information.

The Standard is intentionally loose in recognition that there are a wide variety of information producers and it is trying to be inclusive to all - this brings with it its own problems in interpreting the elements within the Standard.

Information producers and certification bodies come at the process from totally different points of view, particularly when it comes to what constitutes ‘evidence’. The lack of recognition from the certifying bodies of some existing standards (for example CQC) as good evidence of compliance with elements of the Standard is frustrating.

The process and preparing for it is hugely time consuming - but probably worthwhile.

The Standard only applies to England - how will it work with UK wide organisations for example?

How will the Standard make a difference when patients are looking for information online? It may not make any difference to the information they use and search for. Public ‘buy in’ will be a challenge.

Contact Katrina at: katrina.glaister@salisbury.nhs.uk
Anna Sayburn, Patient Editor, Best Health and Editorial Lead for Information Accreditation Scheme, British Medical Journal (BMJ) Evidence Centre (Information Producer)

The role of the BMJ’s Best Health team is to make clinical evidence accessible to the general public. The BMJ Evidence Centre is already very process driven and is very familiar with areas like literature search and appraisal, version control of documents and content management. Processes are very rigorous. When it came to the Information Standard there were certain sections we could sail through but others where that wasn’t the case, for example, there were some gaps in our patient and public involvement work.

Finding the evidence for demonstrating our adherence to the process was difficult at times. We had two meetings with the certification body. Before the first meeting, we did a lot of second guessing about how to interpret the Standard and the processes.

At the pre-assessment meeting, we found we had a different understanding of the requirement to hold an internal audit, to that of the certification body. However, on the day of accreditation there were not too many problems.

It’s also important to remember that the certification bodies are experts at accreditation, not patient information. Some things that seem obvious to us needed explaining to the certification body.

Tips for those thinking of undertaking certification:

• Clarify your expectations of the process and the Standard before you start, if possible with the certification body.
• Use your existing processes - there may be a lot more in place than you think, so use what you have rather than creating new ways to do things.
• Make it easy for the certification bodies - summarise long policies and documents.
• Be aware of the time it may take - getting prepared for accreditation is very time consuming. There is a chance this will become less of a problem as the Scheme develops.

• Think about the outcomes - will the Standard really produce higher quality information? The report for the Picker Institute Europe (Assessing the quality of information to support people in making decisions about their health and healthcare, 2006) could not see how it would.
• Could an organisation that produces poor information actually get through the process and be certified?
• Public recognition is key, but it is not clear what difference the logo and Standard will make.
• The trust rating (by the public) of voluntary organisations and the NHS is already very high. The trust rating of organisations like the Department of Health is a lot lower. Ask yourself what The Information Standard can really do for you.

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Assessing the impact of the testing phase

Picker Institute Europe was commissioned to carry out research to assess the impact of the scheme with those taking part in the testing phase. The result was the publication of the report Information Accreditation Scheme Testing Phase: Assessing the Impact in February 2009. The aim of the study was to assess any effects that the scheme might have on information production processes and the quality of information materials. The study took place during October and November 2008 as organisations were starting the testing phase. The main findings from the study were:

- Many organisations already had well established information production processes and procedures in place prior to the launch of the pilot scheme.
- The overall standard of materials assessed was very high with a mean score of 79%.
- Organisations were very positive about the idea of the scheme and its principles, although many raised concerns over the clarity of the Information Accreditation Scheme Standard (‘The Standard’) itself and exactly what was expected of them. Some still questioned the added value of being an accredited organisation. Other concerns included the implications for smaller organisations and the need to raise awareness amongst the end users of information.
- Most information producers felt that in order to meet the requirements of the scheme they were going to need to make minimal changes to their working practice. Most were undertaking a combination of formalising and extending existing procedures. A small but significant proportion of organisations talked about introducing some new processes which suggests that the scheme could have a greater impact amongst the wider population of information producers.
- Detecting any future improvement in information materials produced by organisations participating in the testing phase of the Scheme is therefore likely to be very difficult.
- Some organisations had found that participating in the scheme had taken considerable time, effort and manpower although others had not found it as resource intensive.
- Opinions on the impact that the scheme might have on the quality of information were mixed. Some felt that the effects on their material would be limited as their information was already of a high standard. Others questioned a direct link between quality of information and quality of processes.

The researchers made a number of recommendations including the development of a strong support network for organisations participating in any future scheme, opportunities to share good practice and exchange experiences and a comprehensive awareness and publicity campaign. A copy of the report can be found at: www.pickereurope.org

31 Information Accreditation Scheme testing phase: Assessing the impact. Picker Institute. 2009
These two schemes are also important to the work of information producers and are likely to have an impact, albeit perhaps indirectly, on the quality of materials and resources.

**The Disability Discrimination Act**

The Disability Discrimination Act is a piece of legislation that promotes civil rights for disabled people and protects them from discrimination. The Act makes it illegal to discriminate against disabled people. The Disability Discrimination Act (DDA) 1995 aimed to end the discrimination that disabled people face in day to day life. It was significantly extended in 2005 and it now gives disabled people rights in the areas of:

- employment
- education
- access to goods, facilities and services
- buying or renting land or property
- functions of public bodies, for example issuing of licences.

Under the Disability Discrimination Act, all businesses and public services have to make reasonable adjustments to the work that they do and the services they offer, so they do not discriminate against disabled customers or employees. The law has been designed so that organisations only have to make reasonable changes, but if they fail to do what is reasonable, a disabled person could take legal action against them for treating them unfairly.

The Act applies to information producers, as it does to any other organisation or business, and means that all organisations must make their services accessible to disabled people. Although the Act does not look at quality directly it does address the need to make information accessible and usable, important factors for any high quality information, and a key component of good practice in this area.

The areas that you may need to consider are:

- signs and labels in your organisation - are they short and easy to read?
- printed materials - do you have different versions of your information resources?
- contacting you - can people contact you in different ways?
- website - is it accessible?

This is an important piece of legislation and you must ensure that the information you provide to patients and the public complies with the Act. The Direct Gov website (www.direct.gov.uk) and the Department for Work and Pensions (www.dwp.gov.uk) have more information about how to make sure you are complying with the Act.
NHS Evidence

Launched in 2009, NHS Evidence is a service that allows those working in health and social care to access a wide range of clinical health information to help them deliver quality patient care. The services NHS Evidence offers include:

- free access to a search engine to help users search for information from credible medical sources, sorted according to relevance and quality
- personalised searches and latest health information updates.

NHS Evidence has an Accreditation Scheme which awards a quality mark to organisations that meet high quality standards in developing ‘clinical’ health information. At present the accreditation scheme covers guidance defined as ‘systematically developed statements to guide decisions about appropriate health and social care to improve individual and population health and wellbeing’. This may include clinical guidelines, referral guidelines, public health guidelines, policy guidance, clinical summaries and best practice.

In the longer term accreditation will be developed for other types of information too.

When someone uses NHS Evidence, those resources developed by organisations who have gained accreditation feature in the top search results, with the Accreditation Mark clearly displayed.

NHS Evidence accreditation is a free service, with no fees for the organisations that apply.

www.evidence.nhs.uk
We welcome your comments and suggestions about this guide - by giving us constructive feedback you can help us to produce higher quality and more relevant information in the future. Please follow the link below to complete the feedback form.

www.pifonline.org.uk

*Thank you for taking the time to tell us what you think.*

If you have comments you would like to make outside the remit of this form, please contact the PiF administrator at:

**secretary@pifonline.org.uk**

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