



*Better information, better
choices, better health*

Putting information at the centre of health

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Document Purpose	For Information
ROCR Ref:	Gateway Reference: 4251
Title	Better Information, Better Choice, Better Health
Author	DH
Publication Date	16 December 2004
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, PCT PEC Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads, Copied to NHS Foundation Trusts for Information
Circulation List	Local Authority CEs, Ds of Social Services, NDPBs, Voluntary Organisations, Arms Length Bodies
Description	A three year programme of action, at both national and local level, to improve access for all to the quality general and personalised information people need and want to exercise choices about their personal health and healthcare.
Cross Ref	Building on the Best, Choosing Health? NHS Improvement Plan
Superseded Docs	N/A
Action Required	Consider implications for planning and practice for future implementation
Timing	N/A
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For Recipient's Use	

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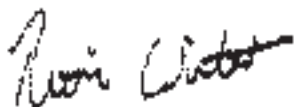
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Foreword

The Government is committed to a modern NHS, one that is better equipped to meet the demands of the 21st century. The recruitment of more doctors and nurses means that more people are being treated more quickly, and people are being offered greater choices about how and where they wish to be treated. People have the power to choose what sort of lifestyle they wish to lead and how it affects their personal health. Supporting such choices will help achieve the vision of a modern NHS as being a service for health and well being rather than just for treating illness.

This time last year, we published *Building on the Best* which set out a vision for supporting greater choice in the NHS. One of the strongest messages from the national consultation on choice, equity and responsiveness was that people said they wanted improvements in the quality and accessibility of information as an essential prerequisite to making informed choices about their health and health care. The need to improve information was confirmed through the recent *Choosing Health?* consultation on public health. Everyone should have access to the high quality information they need to make these choices. *Better Information, better choices, better health* is a programme of action, at both national and local levels, to address this.

Modern public services are built on effective partnerships. In the NHS, the single most important partnership is between patient and health professional. Better health care outcomes are achieved when this partnership is at its strongest – when both patient and health professional share in making decisions about treatment and care. The quality of consent for treatment is improved, people take a more active role in managing their health and health professionals are better supported to provide a level of healthcare and choice that they can take great pride in and that people increasingly expect. Easy, equitable access to high quality information lays the foundation for such partnerships to flourish.



Rosie Winterton MP

Introduction

People get their information and knowledge about health from a wide variety of sources, from family and friends, from television and magazines, from the internet, from doctors and nurses and the NHS itself. That is why this information strategy sets out to make information an integral part of healthcare and also describes a new relationship between people and the knowledge the health service holds. The future is about sharing – sharing of information, sharing of decisions and sharing of responsibility. We know that patient involvement in decision-making improves health outcomes. We know that patients want choices about what treatments they can have, where they are treated, and how they are treated. We also know that there are benefits to all in the public being involved in how health services are provided.

Underpinning all of this is information. It is fundamental to choice and making informed decisions. Without information there is no choice. Information helps knowledge and understanding. It gives patients the power and confidence to engage as partners with their health service.

But we also know that information is not always available, or not available in a medium or language people want. We know that information can be variable in quality and even be contradictory. We know that information comes in many forms – word of mouth, letters, websites, journals, leaflets, just as there are many providers of health information.

This strategy attempts to bring this all together – to ensure information is available to the disadvantaged and marginalised groups, to quality assure and accredit information providers so the information can be trusted, and to extend access to information in a range of media for everyone.

This strategy builds on the commitments set out in *Building on the Best – Choice, responsiveness and equity in the NHS*, which was published in December 2003. It has been developed with the engagement of patients and other stakeholders who shared their ideas and experiences and expertise with great generosity. The work will continue over the next few years both nationally and locally to really make information and choice available to all.



Harry Cayton
Director for Patients and the Public

The need for change

Why is information important?

Information is central to healthcare. From advising on the right daily intake of salt through to getting informed consent for a complex surgical procedure, providing good-quality information is at the core of service provision.

People need access to impartial, high quality information so they can make informed decisions. In the national *Building on the Best Choice* consultation in 2003 nearly 90% of respondents said that in order to make choices about their health and healthcare they needed the right information at the right time with the support they need to use it.

High quality information empowers people. With poor information they cannot make effective choices; and without information they have no real choices at all. A lack of information can be damaging for patients, their relatives, carers and for health professionals. Case Study 1 illustrates this.

Case Study 1

Mr F had a history of heart disease and was admitted to hospital with unstable angina. It was decided that Mr F needed to undergo a coronary artery bypass graft (CABG), and he was discharged and put on a waiting list. In June, he attended an out-patient appointment and saw a registrar and a consultant cardiologist. He was told that CABG carried a 5% risk and angioplasty carried a 2% risk; he therefore chose to undergo angioplasty. The procedure was carried out at the hospital in July. However, during the procedure a coronary artery was dissected and Mr F died. Mr F's son complained that his father had been misled about the relative risks and merits of CABG and angioplasty, and that medical therapy had not been offered as a third option for treatment.

The ombudsman upheld the complaint stating that where clinical options exist, they should be put to the patient to let him or her decide. Further, the risk figures quoted by the consultant were meaningless because the patient was not able to understand them in context.

The Health Service Ombudsman 1st Report 2003/04 session, case E.2333/01-02

What information do people need?

As the Choice agenda rolls out and people become more comfortable with making choices about their own health and healthcare, so the public demand for information will grow. There are two key types of information, both of which people need:

- general information available to all – about lifestyle options, care providers, diagnoses, conditions, self care and treatment options (including risks), standards of care, etc; and
- personalised information – specifically on an individual's own condition, care options and possible outcomes.

When they have good access to both of these, patients and carers are better equipped to:

- improve their health and quality of life;
- take more responsibility for minor ailments where appropriate;
- be aware of treatment options and risks;
- act as equal partners in their care wherever possible.

What this strategy does

This strategy is a three-year programme of action, at both national and local level, designed to improve equitable access to the quality information people need and want to exercise choices about their personal health and healthcare.

The need to provide information is highlighted as a priority in *National Standards, Local Action*, the Health and Social Care Standards and Planning Framework for 2005/6 – 2007/8 (Domain 4 – Patient Focus):

- C14 Healthcare organisations have systems in place to ensure that patients, their relatives and carers
- a) Have suitable and accessible information about, and clear access to, procedures to register formal complaints and feedback on the quality of services
- C16 Healthcare organisations make information available to patients and the public on their services, provide patients with suitable and accessible information on the care and treatment they receive and, where appropriate, inform patients on what to expect during treatment, care and after-care
- D9 Patients, service users and, where appropriate, carers receive timely and suitable information, when they need and want it, on treatment, care, services, prevention and health promotion and are
- a) Encouraged to express their preferences; and
 - b) Supported to make choices and shared decisions about their own healthcare.

A national target has also been set (Priority IV, Patient/User Experience):

‘Secure sustained national improvements in NHS patient experience by 2008, ensuring that individuals are fully involved in decisions about their healthcare, including choice of provider, as measured by independently validated surveys. The experiences of black and minority ethnic groups will be specifically monitored as part of these surveys.’

Principles and aims

The strategy is underpinned by a series of principles, as follows:

People should:

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

To support these principles, the strategy aims specifically to:

- **Embed information as an integral part of delivering healthcare through the entire healthcare system.** Information should be delivered in tandem with care provision and not as an 'add-on' through primary care to secondary and specialist services.
- **Drive up health outcomes for disadvantaged groups.** Helping people in these groups to access, understand and act upon information will help narrow health inequalities and overcome many barriers to improving personal health and using health services.
- **Set out a single approach to information.** Clarity over what information is to be made available nationally will allow local NHS organisations to plan and commission information with confidence and without costly duplication.
- **Empower people to get the right information at the right time.** Timely personalised information will help people make choices to improve their health and help those providing care to give the advice people need when they need it.
- **Help people to confidently participate in healthcare decisions.** Understanding what is happening or likely to happen will help give people the confidence to communicate their preferences and concerns to health professionals.
- **Make information more effective.** The process of delivering information to people is just as important as the information itself. How it is explained directly impacts on how it is received and acted upon.
- **Make communications central to how we care for people.** New and more effective ways of reaching disadvantaged groups will include making information available in new environments (the home, shops, schools, workplaces) and in more accessible formats, for instance plain language, audio, translations, magazines, TV, radio and face to face with trusted community members.

Benefits

Improving information can help us meet service-wide priorities by:

- **Improving patients' experience** – empowering people to take a more active role in their healthcare with information and services tailored to their needs.
- **Reforming emergency care** – through increased awareness and appropriate use of walk-in centres, minor injury clinics and NHS Direct, for example.
- **Improving primary care** – strengthening the relationship between patients and health professionals and fostering appropriate self-care and family involvement.
- **Making better use of waiting times** – for increasing knowledge about condition and improving fitness for treatment, co-operation and self-care.
- **Encouraging greater self-care** – helps people make the best use of health and social care services, thereby reducing inappropriate pressures on areas of the health care system.
- **Delivering policy in the *Choosing Health* White Paper** – by giving people the information they need to maintain and improve their health.
- **Supporting choice of hospital** – increases awareness and access to available hospital choices and drives up standards.
- **Helping people manage their long term conditions** – by providing information to people to support decision-making on their care management.

Benefits for the public, patients and carers include:

- Better access to the information they need, delivered in a way they are comfortable with;
- More personalised information that is directly relevant to them;
- Improved relationships and communication with health professionals;
- Increased ability to take control of their health, understand what is happening and participate more fully in decisions about their care and treatment;
- More good quality information that can be relied on;
- Timely delivery of information so that they get the right information at the right time;
- Information is more readily available in places where people go each day such as supermarkets, pharmacies, libraries and community centres.

For health professionals and NHS organisations, this strategy offers:

- Greater compliance with treatment regimes. Patients who are involved in health care decisions and understand what is happening take a greater degree of ownership and responsibility for their treatment and care.

- Help for NHS organisations to meet requirements of the Clinical Negligence Scheme for Trusts (CNST) standards relating to advice and consent.
- Help for health professionals to meet the duty they have in their professional code of conduct to provide evidence based information.
- Equip health professionals with the tools and support to deliver patient centred care.

And finally there are significant benefits for the healthcare system as a whole:

- **Reduced pressure on primary care** – means a better service overall.
- **Increased public confidence** – as a result of more choice and better outcomes.
- **Better value for money** – making quality, consistent information in a range of languages and formats, nationally available for local NHS organisations to access will significantly reduce the costs of procuring and maintaining the same information locally.
- **Strengthening partnerships** – between statutory and independent sector information and service providers.

How the strategy is set out

The strategy covers five areas where change is needed. Within each area a series of actions and activities are outlined to improve both the quality and accessibility of information as well as the way it is delivered. The areas for change are:

1. Improving access to information for everyone;
2. Improving the quality of information and signposting to further sources and services;
3. Strengthening the relationship between patient and health professional;
4. Clarifying roles and responsibilities in producing and delivering information;
5. Improving the promotion of health and health services.

Information provision – a vision

The strategy is designed to influence the way people seek and use information in informing their healthcare decisions. Successful delivery will mean that by **2008**:

- There is a single approach to information provision, with local organisations using such quality assured national resources as the Patient Information Bank to deliver high-quality and consistent information in a way that meets the needs of local communities.
- People have better access to trusted sources for the information they need, tailored to individual requirements.
- People seek information more proactively, using tools such as the Information Prescription to participate more fully in decisions about their health and healthcare.
- People are better equipped to take full advantage of the Choice initiatives.
- Disadvantaged groups have access to and use information as much as other groups.
- Professionals and healthcare workers communicate better and enable people to take more responsibility for their own healthcare, leading to better health outcomes.
- Local organisations have a better understanding of the importance of delivering high-quality and accessible information, and can do so in a targeted and resource-efficient manner.
- Public confidence in the level of information and support offered by the NHS increases.

Areas for change

1. Information for all – improving access to information

Summary of actions

- Introduce a national translation and interpretation service
- Provide community based support for people accessing information
- Make high quality information available nationally to the public and health professionals
- Make health information available in a wider range of media, such as NHS Direct Interactive
- Make it easy for people to access their own healthcare records

Equity has been traditionally understood to mean providing a universal service. However, patient information is not currently a universal service. As such, it is inequitable and fails to meet the core values of the NHS. But if equity is actually about meeting everyone's needs, then a 'one size fits all' solution does not work. The route to true equity is through greater personalisation of information, making it directly relevant to the individual's circumstances and needs. This would entail provision of a national high quality service that is complemented by local interventions addressing the needs of specific communities, groups and individuals.

Greater diversity is needed in how information is made available to people. Everyone should have the opportunity to access generic health information through ways that are personally acceptable. The way information is written, presented and made available should take into account diversity in ethnicity, culture, religion, language, gender, age, disability, socio-economic status and literacy levels.

Alongside making information available when people want it, including access to their own medical records, a more proactive approach is required in targeting and reaching out with information that is presented in a manner suited to personal needs.

Translation and interpreting service

Language barriers are one of the most fundamental problems affecting the communication and distribution of information. Information should be made available in a range of languages, written or spoken in a culturally sensitive manner, and using appropriate formats, for example audio tape and Braille. The style used should be plain and jargon free – this applies equally to any language, not just English.

“Half a million people whose first language is not English have little command of the English Language”

Health Literacy (A)

NHS Direct have made a universal translation and interpreting service covering all languages available through a framework agreement with Bowne Global Solutions. Any NHS organisation can use this service to commission and access:

- A 24 hour telephone interpretation service in any language
- Written translation of printed materials such as standard letters and patient information leaflets
- British Sign Language interpreters

Further details are available online at <http://nhs.bowneglobal.co.uk>

Community based navigators

Greater diversity is needed in how people are supported to access and understand information. People need different ways, or navigators, to find information and make choice about their health. This is particularly important in reaching people who currently have relatively poor health outcomes.

A majority of health information used and exchanged by people comes from informal networks and is often a mix of many sources including experiential, family and community knowledge and personal skills developed, for example, as a carer or parent. This runs alongside formal information currently provided by the NHS and others. It is important that the role and value people place on lay knowledge is recognised.

“7 million adults nationally have literacy levels and numeracy skills below those expected of an average 11 year old. In London, 23% of 16-60 year olds have poor literacy and numeracy skills.”

Taking Soundings, Health Link (B)

Health advocates, patient care advisors and the Expert Patient Programme successfully support people in making decisions about their health and health care. The recently published White Paper, *Choosing Health*, sets out proposals for NHS-accredited community based health trainers to provide advice and help on making health and lifestyle choices and on accessing other help locally.

The Department will explore ways to support local Primary Care Trusts (PCTs) in deciding with local partners how best to enhance face to face community based support, taking into account the particular needs of their local health economies.

Making high quality information available to all nationally

Nationally, the range of information available will increase in the following ways:

- NHS Direct Interactive
- Health Direct
- Health search engine
- Nationally procured information resources
- Information to help choose a hospital for elective care

NHS Direct Interactive

NHS Direct Interactive will be a health information service in the interactive area on digital TV. The service will enable people to access information (supported by images and some video content) about particular health topics of interest to them, 24 hours a day, 365 days a year.

NHS Direct Interactive is being developed for a number of reasons, including:

- Independent evaluation of the digital TV pilots showed that there is likely to be high take-up of health information via digital TV and that it can reach a wide audience, including low income families who currently have a lower take up of the internet as a source of information.
- Digital TV take-up has grown to around 50% of the UK population and matches levels of home internet access. It is likely to overtake this as the switchover from analogue to digital television draws closer.

The NHS Direct Interactive service is due to launch with 2,500 pages of content. These will cover the following:

- Health encyclopaedia – 280 topics covering illnesses and conditions
- Advice on looking after yourself – self-care information, 80 frequently asked questions, diet, exercise, sexual health and smoking cessation
- Directory of local NHS services – e.g. GPs, dentists, pharmacies etc. from www.nhs.uk database (available January 2005)
- Using the NHS – e.g. how to register with a GP, how to make a complaint, using services such as NHS Direct, articles about current health issues
- Information in a range of languages – text based information (and audio in January 2005) in 16 languages and signposting users to the NHS Direct telephone interpretation service

NHS Direct Interactive will be initially launched on Sky digital TV in December 2004, it will be rolled out onto other digital TV platforms during 2005/6.

Health Direct

Choosing Health pledged to create a new service – Health Direct – from 2007, to provide accessible and confidential information on health choices. Health Direct will be developed as a telephone, online internet and digital TV service. It will be available to people who do not have internet access at home through government funded UK Online Centres which offer free or low cost internet access in a range of community venues.

Health Direct will include links to existing services where they exist – for example information on diet and nutrition (provided by the Food Standards Agency) and support for parents (provided by Sure Start and other agencies).

NHS Direct Self Help Guide

The NHS Direct Self Help Guide is a guide to treating common health problems at home.

The Department and NHS Direct, in partnership with Thomson Directories, have developed a version of the guide that is now included in Thomson Local Directories, and is being delivered to 18 million households in England between April 2004 and April 2005.

The guide covers over 25 of the most common adult and child health problems such as sickness, diarrhoea, fevers and rashes. A 'body key' helps people identify their symptoms and, after a series of simple step by step questions, advises on the best course of action to take. It also includes information on 'What is an emergency?' with advice on what to do. For parents, there is a special section called 'How do I know if my baby is ill?' as well as advice on common children's ailments. The Department of Health, NHS Direct and Thomson Directories are working together on joint promotion of the NHS Direct Self Help guide, as it is rolled out across England.

Nationally procured information resources

In March 2004, NHS Direct Online let a one year contract to BMJ Knowledge for the provision of national patient information materials, 'Best Treatments', which is available via NHS Direct Online. 'Best Treatments' describes the effectiveness of different treatments and explains the risks and benefits of each. It is based on 'Clinical Evidence' a resource used by health professionals, providing patients with the same evidence based information as their health professionals, in an easily accessible format.

"About one third of respondents in the United Kingdom reported receiving conflicting information about their care from different health professionals."

Commonwealth Fund (C)

The Department and NHS Direct Online together with the NHS Information Authority is currently involved in a joint procurement initiative which will lead to the award of a national contract for patient information materials. This procurement exercise will also seek to secure information materials designed to support busy health professionals and improve the consistency of information given to patients. The lack of easy access to up to date, consistent and accurate information on conditions, treatment options and care is a frequent complaint amongst professionals. The procurement is expected to be complete in early 2005.

Information to help choose a hospital for elective care

By December 2005 patients referred by their GP for elective care will be able to choose which hospital to attend from a choice of four or five providers commissioned by their PCT. To help patients make an informed choice of hospital, the website www.nhs.uk/england is being enhanced to provide a range of information identified as important to patients when making this choice. The website currently presents information on:

- Prospective waiting times
- Access information (such as parking and transport)
- Patient experience and quality (taken from the Healthcare Commission performance ratings)

Work is underway to ensure that the information held on the website is accessible to everyone, with plans including more appropriate use of symbols and pictures in addition to other media. The information is also available in printable versions so that it can be given directly to patients.

By 2008, patients will be able to choose any healthcare facility for their treatment that meets NHS standards and prices. National level information on healthcare providers will become more important in a free choice environment as more patients choose non-local hospitals for their treatment. As people become used to such choice and as waiting times fall, they will demand more information on the quality of services and will be more likely to base their decisions on this information. Proposals on the information requirements to better support free choice are currently being developed and will include qualitative data on clinical quality.

Access to health records

Information from their health care records can support people in making choices about their lifestyle, treatment and care. Having access to a recording or summary of a consultation for patients to reflect on later has been proved to be beneficial as part of the decision making process.

Time spent with health care professionals is a key point where changes in treatment and care are discussed and where patients most often make formal decisions about their future care and treatment. Interaction with health care professionals is often the preferred method of information seeking when important and difficult decisions need consideration. The National Programme for IT is working on an NHS Care Records Service and is developing HealthSpace as an easy way for people to gain direct online access to their own personal health record.

HealthSpace

Launched in December 2003, HealthSpace provides people with their own online personal health organiser and will offer a secure portal through which to access all the National Programme for IT services (such as their actual NHS Care Record, Choose & Book, and Electronic Transfer of Prescriptions). People will be able to use HealthSpace to search all NHS sources of information, access support on healthy living and help manage their diabetes or asthma. In doing so, it will help people make the most of current NHS information resources and act as a personal health planning toolkit.

Vision of how technology can contribute to improving health outcomes

Lucy (40) has diabetes. She has registered a profile of interests on HealthSpace, her own secure personal health organiser on the internet. Via HealthSpace, she regularly receives updates about diabetes and consults her online self-management training course and interactive care plan. She keeps a check on blood pressure, cholesterol, blood-sugar, and weight, entering results in her NHS Care Record, checking them against past results. When needed, she receives personalised advice from a telemonitoring specialist about changes to her medicines, diet or lifestyle. She is alerted if she needs to see her GP or pharmacist.

Lucy has asked HealthSpace to remind her to book and attend appointments, to re-order medicines, and to enter test results if she forgets. She attends her GP's specialist diabetes clinic yearly for a check up and periodically a self-carers' support group which also has an online chat room. Lucy's diabetes fits around her career and family, not the other way round.

HealthSpace will be developed to enable people to tailor information and services to their own health needs and wishes, as well as allowing them to view and comment on information health professionals are recording about their health via access to their NHS Care Record when HealthSpace is fully integrated with the NHS Care Records Service by 2006/7.

2. Quality signposting – getting the right information

Summary of actions

- Develop an accreditation scheme so that people can distinguish different types of information
- Develop a health search engine to prioritise and filter different types of information
- Make information about health more widely available in local communities

Good quality information helps lifestyle choices, self care and informed decision making and consent. People can and will get information from a vast range of sources. However, the quality of such sources is variable and there is currently no easy way of distinguishing between high quality and poor quality.

People need support to judge information for themselves; to make a decision as to whether a particular piece of information meets their personal needs. One way of doing this is by developing with members of the public a clear set of quality criteria covering currency of information, its reliability, user involvement in development & accessibility. These will form the basis of a national Information Accreditation Scheme which will be accompanied by public awareness campaigns to support recognition of quality information. Adherence to quality standards should be an essential factor when new information is commissioned.

Vision of how technology can contribute to improving health outcomes

“A survey of the readability of patient information produced by hospices and palliative care units in the UK showed that 64% of the leaflets were readable by only an estimated 40% of the population.”

Health Literacy (D)

The usefulness of information (both written and oral) is significantly enhanced when it points, or ‘signposts’, to other sources of information and support which are of potential relevance and use to the individual or carer receiving the information. Effective signposting also helps tackle inequalities in how and when people access information: healthcare systems are complex by nature and poor communication discourages disadvantaged groups from engaging. Signposting is also critical for professionals – the right information is needed at referral in a quickly accessible form to ensure patients have access to appropriate care pathways. Professionals need access to quality information sources to deliver this.

Information accreditation scheme

People need confidence in the standard and quality of the information they receive. To help people find information that they feel is trustworthy, an easy way to recognise levels or aspects of quality and differentiate between sources of information is needed. The NHS Information Partner programme, run by NHS Direct Online, has sought to provide patients and the public with reliable and accredited information, which they can trust. Development work has been undertaken in partnership with several major cancer organisations, endorsing the need for a formal accreditation process.

The Department and NHS Direct Online 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.

Health search engine

Finding relevant quality information quickly is important to the public and to health professionals. To help sift through the mass of health information available online, we will develop a single search engine for websites from the NHS and NHS Information Partners, in partnership with the National Programme for IT.

Use of the internet to look up health information is common, with around 30% of the UK public using the web to search for health information, and 19% of non-users saying they would use the Internet to look up health information. There is a high level of trust in information produced by the NHS (73%), and search is overwhelmingly the main way of finding information (80%).

Given these, it is likely that a well known, familiar search engine combined with the high quality content produced or licensed by the NHS will prove popular. Work is already underway and the search engine will be available from January 2005.

Greater access to information in the community

Some people will need additional help, tailored to their personal and cultural needs, to access health advice and healthcare. The provision of appropriate support in the local community could be supported through rationalisation and mapping of local resources and to target support where it is most needed in line with PCT local delivery plans. This would take into account the complexities and differences in perspectives of people from various cultures and those with a range of experiences of health and ill-health.

Clearer signposting of information access points in the community can also support this process. The ongoing national *Get the Right Treatment* campaign aims at raising awareness of appropriate access points to the health care system and may be a useful vehicle for supporting local sign posting to local services. Local PCTs may wish to consider how to reach the public in everyday non-NHS environments, for example in supermarkets, pharmacies, schools and libraries, to deliver information more widely and effectively using different media (internet, digital TV, telephone, paper based) and face-to-face support.

3. Personalised information – strengthening the relationship between patient & professional

Summary of actions

- Develop the concept of ‘power questions’ as a way of empowering people to ask the right questions and get information relevant to their personal needs
- Develop the concept of an ‘Information Prescription’ so that people know where and from whom they can get information, following a consultation
- Strengthen the focus on the ‘Copying Letters to Patients’ initiative
- Mainstream communication training and development programmes for professionals to support a culture of shared decision making
- Develop a code of practice for professionals on good communication and information provision

Information needs are often so individual, based on personal experience and circumstances, that assumptions made about these are sometimes inaccurate. Whilst individual needs can be addressed by tailoring information, such resources must be complemented by dialogue and support through direct human contact.

The goal of sharing health care decisions requires better communication on both sides of the professional-patient relationship. People need to have the confidence and skills to articulate their needs. Professionals also need to have the essential skills and time to be able to listen and empathise with patients in order to respond appropriately as part of this shared decision making process.

Some people will need to be supported and empowered to ask questions, become active users of health information and play a greater role in decisions about their health. Children and young people equally have a particular need for information and support to participate in decisions, which is sensitive to their age, stage of development, and balances confidentiality with the parents’ need for information. People value having time to talk with health professionals as well as having access to clear, consistent information sources. Combined with improvements in communication techniques, professionals must be supported with the tools to be able tailor information to individual need.

“Positive outcomes are more likely when interventions combine information sources with some form of direct patient communication”

Review of evidence, DH (E)

People also need support in deciding how to access health advice and care when they need it. Professionals are well placed to support people when they come into the health care system – for example, professionals can use opportunities when patients attend consultations to advise them of alternative sources of treatment and support to best meet their health needs, such as NHS Direct, walk in centres, pharmacies and advice on self care. This approach, in combination with information on local services (for example, ‘Your Guide to Local Health Services’ and GP practice leaflets) is more likely to empower people to make effective use of local services in the management of their own health.

Power questions

One way of empowering people to get the right information and make the most of limited time at consultations is through an “essential set of questions to ask”. These could be integrated with and promoted alongside existing awareness campaigns such as ‘Get the Right Treatment’ and locally by being printed on appointment letters, on patient’s prescriptions and other publications. A corresponding question set designed for clinicians may also be useful to help structure consultations and ensure that all the information needed to make an accurate diagnosis is elicited from patients.

The concept of question sets is intended to empower both patient and health professional to get the information they need from the often limited time available. It is a way of introducing information needs into consultations and forming the basis for greater interaction between patient and professional which is associated with increased patient satisfaction (Reference G).

The Ask About Medicines week in early November 2004, focused on encouraging people to ask questions and participate in decisions about medicines. Empowering people to ask the right questions to get information that is relevant to their personal needs would represent a huge step forward towards shared decision making and reducing health inequalities by helping to overcome communication barriers. The Department will take the lead in developing this concept further with patients and health professionals, and pilot the results throughout 2005.

“When going to see a health professional, two thirds (66%) prepare a list of questions for them only sometimes, hardly ever or never, including 43% who say they never do. Of the 32% who say they often prepare a list, they are more likely to be the more affluent middle classes.”

MORI, ‘Attitudes to Self Care’ (F)

Information prescriptions

The dialogue between patient and professional is critical. Time should be set aside at each consultation to specifically discuss and assess information needs. The concept of an ‘information prescription’ is potentially a practical way of supporting this and raising the importance of information in consultations where time is often limited.

Concerns, fears and information needs based around diagnosis and treatments are discussed, reviewed and recorded in a very personalised way as the notion of ‘prescription’ has connotations of individuality. Information prescriptions are also a useful focal point for a number of NHS activities.

In essence an information prescription, given directly to patients by health professionals, would signpost people to sources of further information and support that are relevant to their condition and circumstances. This could be supported electronically through links to developments within the National Programme for IT and NHS Direct Online such as the national Patient Information Bank.

The Department will explore this further with both patients and health professionals throughout 2005.

Copying letters to patients

If people are to participate fully in decisions about their healthcare, it is only right that they are kept informed about matters that affect their treatment. The Copying Letters to Patients initiative is based on the principle that “letters between clinicians about an individual patient’s care will be copied to the patient” (NHS Plan, 2000) and is an effective way of keeping patients up-to-date with their diagnosis and treatment and demonstrates a commitment to proactive communication.

A continued focus on this will confirm that the NHS is serious about putting patients at the heart of its work. The Copying Letters to Patients initiative signals a major change in culture for the NHS and full implementation is not yet complete across the country. The Department will continue to drive forward this important initiative by working with Strategic Health Authorities and PCTs.

Training to support shared decision making for health professionals

“The education and training of all health care professionals should be imbued with the idea of partnership between the health care professional and patient”

Consumer Association (H)

Essential skills such as listening and empathy can make a significant difference to patient outcomes and are fundamental to shared decision making and partnership care. To support this, communication skills to facilitate shared decision making should become part of core professional training at all levels and not just seen as a bolt on. The skills needed to deliver information are in no way restricted to professional groups: every health care worker

potentially has a role to play in acting as an information source, or signposting to the correct areas. This may be addressed through training, appropriate to the level of contact with the public, patients and carers: this could range from brief instruction as part of an induction programme through to detailed training programmes.

“Education in communication skills must be an essential part of the education of all health care professionals”

Kennedy Report, recommendation 59

The Department will work with NHSU (or its replacement organisation, the NHS Institute for learning, skills and innovation), professional and regulatory bodies such as the British Medical Association, Nursing and Midwifery Council and the Royal Colleges to influence or establish suitable training programmes, ensuring that they complement the National Health Competency Framework proposed in the recent Public Health White Paper.

Code of practice for professionals on good communication and information provision

Although time is often cited as a constraint, even relatively small changes in how information is communicated to patients by professionals can make a real difference to the patient experience of the relationship, leading to positive patient outcomes such as greater compliance with treatment regimes and more appropriate use of services such as NHS Direct or walk in centres. *Choosing Health* states that ‘all clinicians should enable patients to make healthier, more informed choices and ensure that they are offered opportunities that will address prevention as well as treatment and care’ (p.194). This could be supported by developing existing codes of practice for health professionals, based on best practice and setting out behaviours to improve the consistency and effectiveness of communication with patients.

This code, once developed and agreed with professional bodies could be actively introduced and embedded through normal training, appraisal and feedback routes. The Department will consider with professional bodies whether this would be a useful development and how best to go about it.

Supporting change

4. A clear way forward – organisation roles & responsibilities

Summary of actions

- Develop a single, coherent approach to providing information. This will include a national information commissioning & prioritisation framework, supported and steered by a national Information Forum
- PCTs should ensure information and support is targeted to the needs of local communities
- Accelerate development of the Patient Information Bank

People need information on every aspect of the whole healthcare and lifestyle spectrum. There is already a wealth of health information available from a range of sources provided by the NHS, voluntary, independent and private sectors spanning a variety of media channels.

The NHS has a responsibility to provide people with good quality health information to enable them to keep healthy and better understand their conditions, treatment and support options. Some of this information is provided directly by the NHS. However private and Voluntary and Community Sector (VCS) organisations, journals and mainstream media are also a valuable source of health information and have much expertise in providing advice on specific conditions and details of self help groups, amongst other things. People value independent information. The NHS does not and should not have a monopoly on health information. The choices available to patients extend not just to health care options but also to sources of information as well.

The NHS should work in active partnership with the public, VCS organisations and other local and national bodies, to ensure the timely provision and flow of quality information that meets the needs of local communities. To do this effectively and efficiently, a single coherent approach will be developed for designing, disseminating and delivering quality information through suitable methods and formats. The roles in providing information can be summarised as follows:

The **Department of Health** will:

- Nationally procure resources such as information materials where necessary
- Develop tools and disseminate best practice to support service delivery
- Co-ordinate activity and drive forward implementation, ensuring all stakeholders are involved

The **NHS** should:

- Help people access and understand health information, providing support in making choices for those who want it
- Make high quality general health information available locally and personalised information available to individuals

- Commission where necessary quality assured information from the voluntary and private sectors and make it freely available to patients when they need or want it

For instance, the Department, in partnership with NHS Direct Online, will take the lead in developing tools such as the Patient Information Bank, nationally procuring quality information and materials to populate it, and promote its use to local NHS organisations. Locally, NHS organisations can access these resources to help provide good quality information directly to individual patients at the point of need.

Another example would see the Department opening discussions with professional bodies to draw up a code of practice for health professionals relating to communication with patients. Once agreed, the Department will engage with NHS organisations to promote and introduce the code of practice into training and appraisal schemes.

National information commissioning and prioritisation framework

A wealth of information is being developed and delivered to people by a range of organisations across the country. There is not however an overarching method of prioritising when and where resources could be focused to improve the information available to people.

There is a clear need for a national information commissioning and prioritisation framework, the main benefit of which would be to bring clarity to who is responsible for doing what in terms of designing, disseminating and delivering information at both national and local levels. This would eliminate local duplication of information which can be made available nationally, and through clear commissioning arrangements will maximise the contribution VCS organisations can make. It will establish criteria such as levels of quality that any information or services that are commissioned, both nationally and locally, ought to meet. The prioritisation element of the framework will take into account the need to develop ways of supporting the process of giving and receiving health information as well as developing new items of information.

A national information forum (comprising representatives of major information providers from both the statutory and independent sectors, patient organisations and professional and regulatory bodies) will be established to have oversight and steerage of this framework. The forum will have a key role in ensuring interoperability between information providers, identification of commissioning priorities, and supporting and promoting innovation and good practice.

Local action

Support for people accessing, understanding and using information as part of their care is often seen as activity that may happen over and above standard care provision rather than as a standard core activity for those who plan and provide care services, either directly or indirectly. As outlined in the 2005-08 Planning Framework (p.46, paragraph 13), 'PCTs should ensure that adequate patient information and support processes are set up and, particularly, to provide targeted support for hard to reach individuals and communities, including black and minority ethnic groups'. PCTs should consider information provision and support as being an integral part of core business and as such, may wish to map the information and support available against locally identified health improvement priorities to enable provision to better meet the needs of local populations.

People may access information from a broad range of sources, not just the NHS. Those who may not currently access health information could be better targeted by proactive use of information points in the community. PCTs may wish to work in partnership with local strategic partners to develop a consistent approach across the local health economy so that people have access to a broad range of information sources and support which is sensitive towards ethnicity, language, gender, age, disability, socio-economic status and literacy levels. Local delivery plans (LDPs) could be natural vehicles for PCTs to articulate their approach towards ensuring that information and support is available and relevant to local needs.

Choosing Health signalled development of a tool to assess local health and wellbeing that may help PCTs audit local needs and jointly plan local solutions with their strategic partners.

Patient Information Bank

A great deal of NHS time and resources is spent producing across the country, with varying degrees of success, similar information about conditions and treatment. NHS Direct Online is leading a project – the Patient Information Bank – to make available as an electronic resource to the whole NHS, a bank of accredited information on conditions and treatment in a print ready format that can be tailored to reflect local needs.

This resource will:

- help support clinicians to deliver consistent, high quality, evidence based information for patients
- support NHS Trusts in meeting the CNST Clinical Risk Management Standard for Advice and Consent
- reduce local duplication of information which can be made available nationally.

To maximise the potential benefits, the development of this resource must be accelerated and the Department will explore with NHS Direct Online ways of doing this.

5. Improve the promotion of health and health services – making communications central to how we care for people

Summary of actions

- The NHS should work with partners to increase the frequency and access of healthy living and local service information
- The NHS should make information available through their local contractors, in particular pharmacies who will support six campaigns a year
- The NHS should continue to use and localise the national Get The Right Treatment Campaign
- The NHS should share best practice where good information provision is demonstrating real benefits for professionals and patients
- The Department will segment the population and identify best practice for communicating with each audience
- The Department will make health editorial content available for the NHS to adapt for their own communications activities
- The Department will review and strengthen the marketing support it provides to the NHS

People having the right information about their health care at the right time and with the support they need to use it, has already been identified as a key driver for making the NHS more responsive to patients. However, there is much more that could be done to enable the NHS to systematically target communications – talking to different types of people at times when they are listening in language they understand.

An information revolution

The NHS is doing more to reach people locally than ever before:

- “Your Guide to the NHS” distributed by PCTs to every household in the country, is now in its third year.
- The NHS Direct Self Help Guide section of Thomson Local Directories has put over 60 pages of health advice into more than 16 million households.
- The *Your Life* and *FIT* magazine pilots which the Department has sponsored between Dr Foster and the local NHS, show what can be done to present information on healthy living and local health services in an accessible way.

At the national level, NHS Direct and NHS Direct Online already provide a great deal of information to the public on health. In addition, the Department is working with Dr Foster on national publications which will target health information at particular segments of the population, including:

- *Prime* which focuses on older people with health concerns.
- *You're Pregnant* for young less affluent mums to be.
- a health supplement in partnership with Metro newspaper targeting a younger readership.

The lessons learned from these projects and from independent research with NHS communication leads will help the Department to support the NHS to deliver better, more targeted and more frequent information to the public.

To deliver an Information Revolution, the NHS should work:

- in partnership with the private and voluntary sectors to create health care and healthy living information products that talk to public and patients in their language.
- with industry, commerce and the wider public sector to deliver these products in the environments where people, work, live, shop, learn and play.
- more closely with the media, both national and local, to deliver the health messages.

As highlighted in *Choosing Health*, segmenting communications to target groups with common health literacy, lifestyle and communications preferences makes it more likely they will receive the message and act upon it. To support this, the Department is working to identify different groups in the population and identify best practice for the NHS in how to communicate with each group. It will also make real life health editorial material available for the NHS to adapt for its own communication activities.

Consistency and repetition are also important. We need to keep giving consistent messages so that people are more likely to receive, recall and act on them. The NHS should work with partners to increase the frequency of and access to healthy living and local service information.

The Department will continue to develop innovative approaches to getting health messages across including:

- the use of NHS Direct Interactive;
- to build on pilot work in Slough with Dr. Foster, using geo-demographic and Hospital Episode Statistics (HES) data to identify and target those most at risk of developing diabetes.
- exploring the possibility of extending agreements with national high street chains that might be suitable outlets for the NHS to reach the public.

Campaigns

Pharmacies

From April 2005 the national pharmacy contract will place greater emphasis on pharmacists pro-actively taking part and contributing to national and local campaigns. People visiting pharmacies will be given advice for up to six campaigns a year. Primary Care organisations will determine the topics of campaigns and provide appropriate support in the form of briefing packs, patient literature and in-store displays.

Get the Right Treatment

The national *Get The Right Treatment* campaign will continue to raise awareness of the different points of access to the health care system. Research tells us that people need more detailed information about the range of services available locally and how to access them. The NHS may wish to consider this in their local planning, design and implementation of campaigns.

Choosing Health

Choosing Health pledges funding for specific campaigns through non-government organisations like the British Heart Foundation, Cancer Research UK and Age Concern, to help extend the number of sources that actively and consistently promote health.

Supporting best practice

Health professionals play a central role in providing information to patients. Without their support the true benefits of improving patient information cannot be fully realised. Where good information provision shows real benefits for professionals and patients, this should be identified and shared so others can build on best practice.

A pilot will test whether power questions and information prescriptions will make information more accessible to the public. Once these programmes are implemented more widely there will be a need to raise awareness of these products and their benefits with health professionals and the public.

Delivery timetable for action

The strategy will follow a three-year timetable. This last section outlines how the strategy will be delivered and shows the roles played by stakeholder organisations. It also highlights what must be achieved at each stage and what end results are expected.

The Department will co-ordinate the activities set out in the strategy and will produce a detailed framework to help equip stakeholders with the support and tools they need to deliver change.

Role of key stakeholders

The Department recognises that these organisations are key in shaping and delivering the actions set out in this strategy. While their individual remits vary, for each of them the provision of high-quality information is a vital part of their role.

Department of Health	Professional and regulatory bodies	NHS Direct Online
Primary Care Trusts, Children's Trusts	NICE	NHS Direct
Strategic Health Authorities	National Programme for IT	GP Practices
NHS Trusts NHS Foundation Trusts	Health Care Commission	Local Government Association
Social Care providers	Modernisation Agency (or the NHS Institute for learning, skills & innovation)	Sure Start, Children's Centres
VCS organisations	NHS Alliance	NHSU (or the NHS Institute for learning, skills & innovation)

Next steps

This section outlines five key areas which complement the areas for change highlighted in the strategy. They will act as checklists for action:

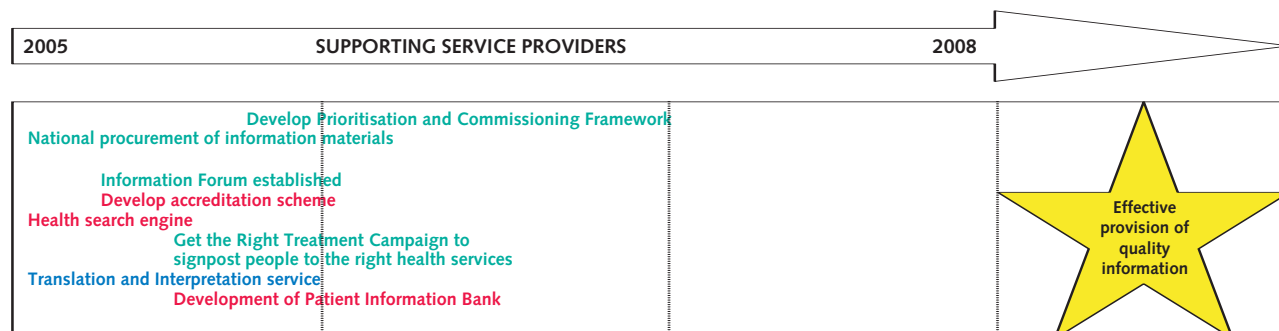
- supporting service providers
- empowering people
- developing professional standards
- local activities
- monitoring arrangements

To ensure successful delivery of the strategy, all five areas will be addressed.

The following diagrams comprise a timetable for delivering the activities set out in the strategy, grouped around specific areas and key stakeholder groups. The organisations listed above have been grouped together and colour coded to show who will lead on particular activities.

Department of Health
Local health care organisations

Arms length, professional and regulatory bodies



For high-quality information to be made widely available to the public, it is essential that service providers are supported, not just in terms of having access to information but also in ensuring that this access is resource-efficient. To this end the strategy will look to co-ordinate the delivery of specific projects to help the retrieval and presentation of quality information. Some of this work is already under way and will be built on, strengthened and co-ordinated with other related areas. The Department will work in partnership with key organisations to design pooled information resources and to provide tools to produce the information in useful formats.

Further activities include:

- working closely with NHS Direct and the National Programme for IT in designing Health search engine and providing extra resources for the Patient Information Bank;
- researching the best approach for an information accreditation scheme;
- developing ways to publicise access to information sources and services;
- researching how healthcare workers access and use accurate and reliable information.

All these measures will be based on sound research and will be continuously evaluated to ensure they are working. We will also produce a communications programme to help local providers make best use of these resources.



Effective use of high-quality information is most successful where people and service providers both play an active role. These measures have been designed to support and develop peoples’ skills in accessing and using information, as well as strengthening the skills of information providers in supplying high-quality personalised information. It is also important to recognise the role played by wider community partnerships in providing people with information and support.

These steps represent major changes in behaviour and they will take time. We will co-ordinate across groups to ensure there is fair access to information at every stage.

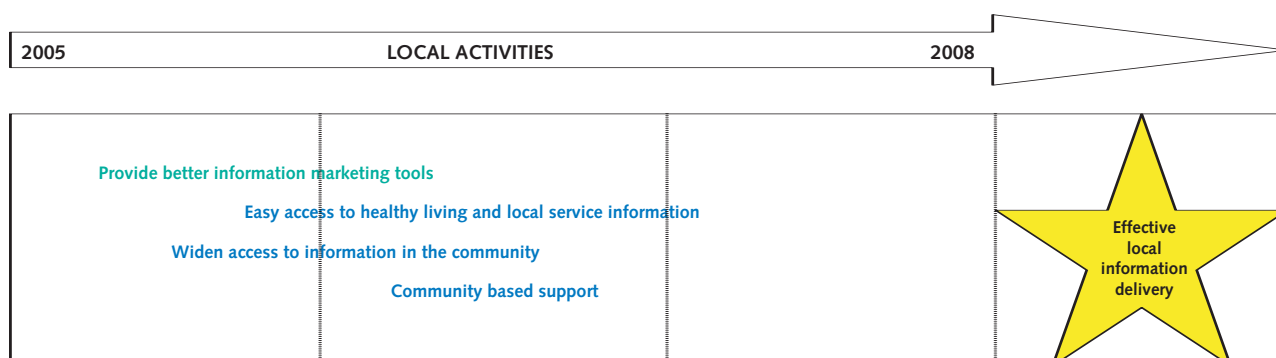
Further actions include:

- working with professionals and the public to shape the design and format of the tools outlined above;
- piloting these tools in a variety of settings across population groups and continuing this research as work extends into wider communities;
- using such evaluation methods as patient surveys to continuously monitor and assess the impact of these measures as a basis for future improvement.

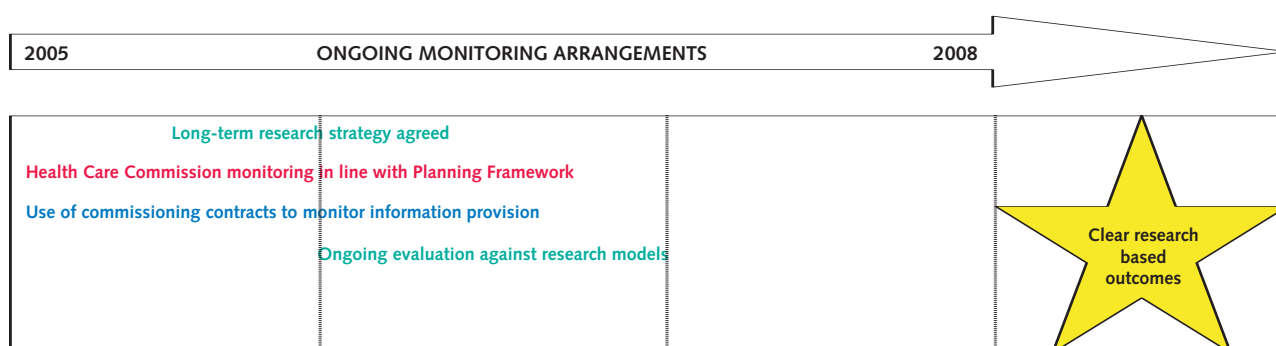


High-quality information is more effective if it is skilfully delivered and interpreted by healthcare workers and professionals. Many healthcare workers have these skills, but there is no clear consistency and standardisation. The activities set out in the strategy are designed to bring communication and information provision techniques to the forefront of all training, so they become essential components of learning and appraisal programmes, not just ‘add-ons’.

This will entail a longer-term cultural change which can be achieved only with the support of relevant bodies. The Department will work with professional and regulatory bodies and healthcare organisations to support the design of appropriate programmes of learning and will actively promote best practice.



Alongside national activities, local NHS organisations should be in a position to meet the health information needs of their population, taking into account local planning and public health priorities. This will form the basis for providing fair local access to health information and services in way that is sensitive to the barriers some groups face.



A clear, research-based evaluation model will underpin delivery of the strategy. This will be used to demonstrate the benefits in practice and also to highlight areas for further action or improvement. We will also explore research on the following key areas with an emphasis on fair access to information:

- how people use information;
- how people judge the quality of information;
- the effects of changing peoples' information-using behaviour, both in terms of health outcomes and benefits to service provider;?
- the barriers preventing people using the information they need;
- whether the quality of information provision is improving.

Robust and ongoing evaluation will ensure that the activities set out in the strategy become part of a continuous improvement in quality of services. We will discuss with the Health Care Commission how best to evaluate outcomes as part of their monitoring for the Health and Social Care Standards (C14, C16 & D9). Commissioning organisations may also wish to monitor locally the quality of information products or services through service-level agreements.

Summary of activity in the strategy

Activity	Lead	Working with	Timescales
Information for all – improving access to information			
National translation & interpretation service	NHS Direct	Bowne Global Solutions	Now
Community based navigators	DH	PCTs	Work begins 2005
NHS Direct Interactive	NHS Direct Online	DH	On Sky by December 2004, other providers during 2005/6
NHS Direct Self Help Guide	NHS Direct	Thomson Directories	Now
National procurement of information resources	NHS Direct Online & NHSIA	DH & National Programme for IT	Complete by end of March 2005
Information to support choice of hospital	DH	NHS Information Authority, PCTs	Now
HealthSpace	NHS Direct Online	National Programme for IT	Now. Online access to care records by 2006/7
Signposting and quality – getting the right information			
Information accreditation scheme	DH & NHS Direct Online	PCTs, VCS organisations & regulatory bodies	During 2005
Health search engine	NHSIA	DH & National Programme for IT	January 2005
Widen access to information in the community	PCTs	Local strategic partners	Work begins 2005
Personalised information – opening the relationship between patients & professionals			
Develop & pilot 'Power Questions'	DH	Professional bodies, local NHS organisations	Work begins 2005
Develop & pilot 'Information Prescriptions'	DH	Professional bodies, local NHS organisations	Work begins 2005
Copying letters to patients initiative	SHAs & PCTs	DH	Now
Mainstream communication training for health professionals	DH	Professional & regulatory bodies, NHSU, local NHS organisations	Work begins 2005
Code of practice for professionals on good communication with patients	DH	Professional bodies, local NHS organisations	Work begins 2005

Activity	Lead	Working with	Timescales
Organisational roles & responsibilities			
Commissioning & prioritisation framework	DH	PCTs & VCS organisations	Work begins 2005
Matching information provision to local needs	PCTs	DH, SHAs, local strategic partners	Work begins 2005
Patient Information Bank	NHS Direct Online & DH	Local NHS organisations	Available early 2005
Communications & support			
Increase frequency & access to healthy living and local service information	PCTs	Local strategic partners	Already underway
Make information available through local partners, e.g. pharmacies who will support 6 campaigns a year	PCTs	Local strategic partners, pharmacies	April 2005
Local use of the national Get the Right Treatment Campaign	PCTs	DH	Now
Share best practice in good information provision	PCTs	DH	Now
Segment population and identify best practice for communicating with each group for PCTs	DH	PCTs	April 2005
Make health editorial content available for use locally	DH	PCTs	April 2005
Review & strengthen marketing support provided to the NHS	DH	PCTs	April 2005

Appendix: background and references

This strategy was developed through discussions and recommendations of four task groups, each comprising key stakeholders, including those from the community and voluntary sector, patient organisations, professional bodies and cross-government and NHS providers. The task groups started their work by looking at a summarised evidence base commissioned by the Department of Health.

The references used in the strategy are as follows:

- (A) S. Sihota & L. Lennard, *'Health Literacy'* (National Consumer Council, 2004), p.15
- (B) Health Link, *'Taking Soundings, Testing the views of patients including hard to reach groups'* (2004), p.6
- (C) First report and recommendations of the Commonwealth Fund's International Working Group on Quality Indicators (June 2004), p.86
- (D) S. Sihota & L. Lennard, *'Health Literacy'* (National Consumer Council, 2004), p.23
- (E) W. Anderson, *'A rapid review of the evidence relating to patient information and communication'*, (DH, August 2004), p.5
- (F) MORI, *'Attitudes to Self Care – Baseline Study'*, Research study conducted for the Department of Health, October 2004
- (G) MK Buller & DB Buller, Physician's communication style and patient satisfaction, *'Journal of Health & Social Behaviour'*, 28, pp 375-388
- (H) Consumers' Association, *'Patient Information, What's the prognosis'*, p.17



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265325 1p 1.5k Dec 04 (CWP)

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