NHS SCOTLAND

Patient Focus and Public Involvement

SCOTTISH EXECUTIVE

Working together for a healthy, caring Scotland

PATIENT FOCUS AND PUBLIC INVOLVEMENT

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Introduction

In December 2000, *Our National Health: A plan for action, a plan for change* was launched. The plan outlined how we proposed to improve the health of the people in Scotland, deliver high-quality health and social care services, and address inequalities in health more effectively.

To achieve these aims there has to be a culture change in the way the service interacts with the people it serves and the way services are delivered. It is no longer good enough to simply do things *to* people; a modern healthcare service must do things *with* the people it serves.

What are we trying to achieve?

A service where people are respected, treated as individuals and involved in their own care.

A service where individuals , groups and communities are involved in improving the quality of care, in influencing priorities and in planning services.

A service designed for and involving users.

This framework aims to help make this change in culture a reality. It has the needs of patients' built into its heart. Success in achieving its aims will ensure that the health service is responsive to these needs and is focused on action to meet those needs. It is an important part of the quality agenda of continuing service improvement.

Defining "a patient-focused" NHS

A "patient-focused" NHS is a service that exists *for* the patient and which is designed to meet the needs and wishes of the individual receiving care and treatment.

"*We want to work with the NHS to ensure that a patient focus is embedded in the culture. To make this happen we will ensure that listening, understanding and acting on the views of local communities, patients and carers is given the same priority as clinical standards and financial performance."*

Our National Health: A plan for action a plan for change (p50)

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the word individuals should be seen in its broadest sense and can refer to health service users, patients, members of the public, carers, volunteers etc.

A patient-focused NHS, therefore, will:

- maintain good communications, including listening and talking to patients, public and communities
- know about those using the service and understand their needs
- keep users of the service informed and involved
- have clear, explicit standards of service
- maintain politeness and mutual respect
- have the ability to respond flexibly to an individual's specific needs
- ensure effective action is taken to improve services
- talk with users, the wider public and communities.

These characteristics need to be kept at the forefront of delivering change in the NHS.

A Framework for Change

This paper provides a framework for change, that must cover the entire breadth and depth of NHSScotland. Much action is already underway to achieve patient focus and public involvement, but much remains to be done.

This framework has been subdivided into four broad themes:

- Building Capacity and Communications
- Patient Information
- Involvement
- Responsiveness.

These themes are complementary, and do not stand in isolation. In fact the complementary and overlapping nature of the themes adds to the potential strength of the programme, as different aspects build on and link to one another.

Building Capacity

Key Theme

Having the ability to take effective action to improve services

Our National Health aims to achieve a major improvement in health services in Scotland. New structures, systems and processes are not sufficient to deliver the plan. Many staff will need to develop new relationships with the people and communities they serve.

The success of previous attempts to put the patient at the centre of service delivery has been patchy, sometimes failing at the implementation stage or even sooner. We propose to overcome this by building and sustaining the necessary skills at individual, organisational and professional level. If the principles and changes set out in *Our National Health* and in this framework are to succeed, staff will need training in communication skills and a patient focused approach.

Supporting a change in thinking and working that *does with* rather than *does to* the patient will also require training and support for the public, to enable the public to:

- take an active role in their own care
- make an active contribution to service development using personal experience
- be involved in discussions with the NHS about wider health issues.

Communications

Key Themes

Clarity and sensitivity
Maintaining public confidence

Communication skills are such a fundamental part of our everyday life that they are often taken for granted. Communications link every part, or process, of health and healthcare. Effective communication with patients and their carers when they are anxious and vulnerable is a difficult skill which requires care and attention. Failure to communicate can have a very significant impact on an individual's treatment and general wellbeing.

NHSScotland needs to make sure that communications are effective at all levels. The principles of good clear communication we expect from the NHS are:

- openness and honesty
- the use of appropriate language for each group or individual
- sensitivity and understanding
- use of the appropriate method of communication for the situation or the individual
- listening to what is said and being sensitive to the reaction of others
- providing effective feedback.

Communication between patient and professional

Patients rightly expect to be given relevant information that is clear, and advice that is understandable. We expect clinical and other staff to have strong communication skills.

Communication training programmes will be developed and enhanced for all NHS staff.

Communication between NHS and the Public

Failure to follow the principles of good communications can lead to an organisation appearing evasive and losing the confidence of its community. Problems must not be hidden and must be dealt with as effectively and quickly as possible. At the same time organisations should not be afraid to be positive when they are successful in solving problems or providing a service that meets with patient approval.

Communication between NHS and other organisations

NHS organisations need to have a clear and explicit approach to communications with other organisations, community planning partners, voluntary organisations, and local communities. Joint working is key to the successful delivery of *Our National Health* and NHS organisations will require a range of methods of communication that will keep people informed about health services and keep the NHS informed of public opinion about the services provided.

BUILDING CAPACITY and COMMUNICATIONS - ACTION POINTS

The Scottish Executive Health Department will

- invest £5million over 3 years to help NHS staff and communities work together to improve services and make communication more effective in NHSScotland.

- help and support a programme of development and training for the NHS and communities that will be sustainable at local level. *Involving People*, the first phase of this programme, will be complete by March 2003.

- help and support the development of training as part of the *Involving People* initiative.

NHS organisations must

- ensure that the principles of a patient-focused approach, including effective communications and public involvement, are incorporated into training and development activities, including:

  - induction programmes
  - pre-qualification professional training
  - continuous personal development and professional training
  - leadership development.

- implement staff training programmes locally.

NHS Boards and Trusts must

- establish an intensive communications training programme for all staff.

- demonstrate that they have developed a diverse range of modern and appropriate methods for communicating with their local communities.

Patient Information

Key themes

Keeping people informed
Giving people choices

A high proportion of complaints received by the NHS result from inadequate information or poor communications. Feedback from the public repeatedly emphasises a need for better information about their health, their treatment, the options for care, and the availability of health services. Without this information it is impractical to expect patients to make informed choices or take more responsibility for their own health.

Patient Information Initiative

Patient information within Scotland is provided from a wide variety of sources and a mechanism is needed to ensure that the information is of a suitable quality and that good practice is shared.

A Patient Information Initiative is to be established to raise the quality and widen the range of patient information and improve access to it.

This Initiative will:

- assure the quality of patient information, based on a range of evidence
- involve and engage with other sources of expertise such as expert patients
- make information accessible and available in a variety of formats
- link to future developments (e.g. NHS24 on-line).

Key to this is the development of a quality assurance process that works from common standards and guidelines but retains local flexibility where possible.

Guidance and the development of standards for the development of high-quality information will be based on the work recently completed for the Executive by the Health Services Research Unit based at Aberdeen University.

Patient Information Network

A key feature of the Patient Information Initiative will be the establishment of a network of information specialists from across Scotland.

The Public Information Network will take responsibility for:

- leading and directing the development of patient information
- managing the establishment of a core databank
- developing and overseeing the quality assurance process

- developing and supporting a range of approaches to the distribution of information
- sponsoring a training programme for Patient Information
- exploring opportunities for research and development in liaison with the Chief Scientist Office
- developing and producing, in liaison with NHS24, high quality self-care advice
- linking with clinical effectiveness bodies to ensure appropriate and accessible information is included on the patient content of guidelines.

The network arrangements are part of a developing process. We will review the arrangements in 3 years, allowing time for the full rollout of NHS24 and the development of other aspects of this change programme.

Improving Access to Information

The Patient Information Network will also play a key part in improving access to both the traditional paper-based forms of information and to new technologies, such as web-based information.

A network of innovative health information access projects will be established, including the development of information through NHS24.

What about the Patient's Charter?

The UK-wide Patient's Charter was launched in 1991, and unsurprisingly no longer reflects the current position within NHSScotland.

We will replace the Patient's Charter with a more comprehensive package that will incorporate:

- a guide to the NHS
- standards focusing on patient entitlements, based on generic standards produced by the Clinical Standards Board for Scotland
- the responsibilities of patients using the NHS
- information about medical records, legal rights, and the complaints procedure.

The package will be produced in partnership with NHS Boards to ensure it is relevant for local people and communities.

The Scottish Consumer Council has been commissioned to produce this package in partnership with Health Councils and the public.

Information about Patients

Another aspect of NHS information is personal patient information. The development of electronic health information will include pilot projects to explore the possibility of introducing smart cards for patient-held records. The important advantage for involving people offered by smart cards is that the security technology makes it

possible for both patients and clinicians to have access to the record. Hence we are currently considering a trial which will involve online shared care ante-natal records, accessible by the patient as well as her clinicians. The smart card "key" also gives access to additional health educational material, and the potential for an area for patients themselves to record information important to them.

INFORMATION - ACTION POINTS

The Scottish Executive Health Department will

- invest £3million over 3 years to inform people better about their health, their treatment, their options for care and the availability of health services.
- facilitate the establishment of the Patient Information Initiative and network of patient information specialists
- publish guidance to support the development of quality assured patient information in January 2002 together with 3 patient information leaflets developed and tested as part of the development process.
- roll out NHS24 beginning in April 2002, providing advice and information about health and healthcare services
- pilot and evaluate the use of smart cards.

The Scottish Consumer Council will

- develop a replacement to the Patient's Charter for publication by June 2002.

Involvement

Key Themes

Knowing about health service users
Talking and working with users, the public and communities

Greater patient and public involvement is a very important part of improving the quality of service provided by NHSScotland.

Effective public involvement can

- act as a catalyst for change
- help achieve a major improvement in the health of the public
- help strengthen public confidence in the NHS.

Public involvement has often been seen as a low priority issue. NHSScotland must make public involvement a day to day reality, one that is fully integrated across the different levels and different organisations of the NHS.

The National Level

At a national level, specialist groups are expected to include lay representation. This practice will be monitored and extended where appropriate.

At NHS Board Level

Each NHS Board has a designated director with responsibility for public involvement. Whilst this lead responsibility is important, there is a need to ensure that public involvement is embraced by the whole organisation. Active support and action should not be restricted to one individual, and there should be much wider ownership.

NHS Boards will work closely with community planning partners and voluntary organisations in developing public involvement procedures.

The voluntary sector is complex and wide-ranging with many complementary areas of service delivery. These need to be utilised effectively.

Different approaches and methodologies to Public Involvement

The learning from *Designed to Involve*, an Executive-funded project to support the development of public involvement in primary care, will be used to extend training and support for public involvement across the NHS.

Public Involvement in service change

NHS Boards will be expected to take a pro-active and positive approach to public involvement on issues of potential service change. This is an important area for active ongoing public involvement and one where effective communications is essential.

Involving the public should not be seen as something that has to be done at the end of a process, but something that is part of an integrated process of communication and discussion; where communities, patients, public and NHS staff have opportunities to influence decision making. An inclusive process must be able to demonstrate that the NHS listens, is supportive and takes account of views and suggestions.

Revised guidance on public involvement in service change will be issued by March 2002.

Local Health Councils

The requirement for NHS Boards to engage more directly with the public will impact on the role of Health Councils. Health Councils have also recognised the need for change and for greater clarity about their roles and responsibilities. This is particularly important as different councils have, over time, focused on different areas of interest and often interpreted their role very differently. We will give clarity to the role of Health Councils that takes account of the changes in NHSScotland.

Health Councils believe their credibility with the public is jeopardised by the current arrangements, as NHS Boards select and appoint Health Council members and staff. The revised proposals will address this issue, and guidance will be provided in order to address any issues concerning legislation.

We will consult on a suggested new role and structure for Health Councils, which will have 3 main functions

- **Assessment** - ensuring that the voices of patients and the public are heard and the services respond
- **Development** - supporting development of good practice in areas of public, patient and community involvement
- **Providing feedback** - supporting patients, carers and the public to make their views known.

It is proposed to establish **a National body with a local presence – the Scottish Health Council.**

This body will incorporate:

- a national office responsible for infrastructure, staff support, training and dissemination of good practice.

- local offices, with a small core of staff appointed by the national body and non-executive members locally appointed in conjunction with the national body, working in each NHS Board area.
- a Health Service Users Forum in each NHS Board area. This forum will appoint the non-executive members of the local office of the Scottish Health Council.

INVOLVEMENT - ACTION POINTS

The Scottish Executive Health Department will

· invest £3million over 3 years to involve health service users, the public and communities at every level

· establish a network of staff and public engaged in public involvement by March 2002

· provide advice and support to areas wanting to develop their approach to public involvement

· publish a 'toolkit' of public involvement methodologies by March 2002

· establish a voluntary sector forum to re-energise the relationship between the NHS and the voluntary sector by May 2002

· publish revised guidance on public involvement in major service change by March 2002

· provide guidance, for use within the Health Department, on involving people at a national level.

· consult on proposals to establish the Scottish Health Council.

NHS Boards will

· be expected to produce a sustainable ongoing framework for public involvement by March 2003

NHS Boards and Trusts will

· strengthen existing partnerships and ensure opportunities for patient and public involvement are integrated and in-line with policy for that Board area.

Responsiveness

Key themes

Flexibility in responding to individual needs
Maintaining mutual respect

Previous attempts to make the NHS more "patient-friendly" may have failed because patients felt excluded or patronised. NHS organisations must respect the views and needs of individuals, the wider public and local communities and reflect this within their strategies. They will therefore provide:

- a range of opportunities for the public to provide feedback on local health services
- flexibility and sensitivity in responding to specific needs
- mechanisms for taking account of and acting upon complaints and concerns
- ways of sharing positive messages about good practice.

Considering feedback from the public

Feedback on the services provided by the NHS can and should be solicited in a range of ways. The commonest approach is to use a survey. A well-targeted survey can provide useful data on specific elements of the patient experience; however, it can also be superficial and not address the issues that are important to patients. Where a survey is superficial, or when a survey fails to result in action, the survey will be of little value.

The Scottish Executive Health Department will publish guidance on the use of patient surveys in early 2002, based on research recently carried out in conjunction with the Scottish Consumer Council. This guidance will be supplemented by information on alternative ways of soliciting feedback.

Responding to specific needs

NHS Boards need to develop processes to identify the action required to make the service better and to be more responsive to the needs of patients. This is particularly important for services responding to patients with additional or special needs.

Advocacy is recognised as an important way of enabling people to make informed choices and remain in control of their own health. *Independent Advocacy: A Guide for Commissioners* issued to NHS Boards early in 2001 provided tools to enable NHS Organisations to meet their duty to work with local authority partners to develop advocacy arrangements. These arrangements were to be in place by December 2001.

Innovative advocacy programmes have been developed for clients with specific needs. These include:

- Mental Health service users have helped develop Patient Councils to complement the individual advocacy work already underway.

- The *Allies in Change* programme developed this work further.

- *Partners in Policymaking* has helped disabled adults, and the parents of disabled children, to develop leadership and advocacy skills and abilities to help improve awareness and responsiveness within service providers.

The Scottish Executive Health Department will support the rollout of further initiatives through the development of *Partners in Change.* This initiative has already had some success in delivering patient views on diabetes to policymakers within NHSScotland and NHS organisations are currently testing and developing potential projects for implementation in March 2002.

Responding in a culturally competent way

In December 2001 the Scottish Executive Health Department published a 'stocktake' of the services it provides for people from ethnic minority backgrounds, as its "*Fair for All"* Report. This report forms the keystone of a programme designed to encourage NHS Organisations to take action to ensure a "culturally competent" NHSScotland, ensuring sensitivity to the cultural and religious needs of ethnic minority groups.

Taking account of and acting on complaints

Complaints are part of a broader spectrum of patient opinion on NHS services. The potential for learning from complaints is great. Equally important is the need for complaints to be dealt with promptly and with adequate respect for the concerns of the individual.

The current UK-wide complaints procedure has been fairly widely criticised. It has been independently evaluated on a UK-basis and discussions are now underway that will lead to the development of a Scotland-specific procedure in 2002. This new procedure will fulfil the commitment in *Our National Health* to establish a complaints procedure that is "credible, easy to use, demonstrably independent and efficient".

RESPONSIVENESS – ACTION POINTS

The Scottish Executive Health Department will

- invest £3million to support flexibility in responding to individual needs and maintaining mutual respect
- continue support for advocacy development, *Partners in Policymaking, Partners in Change* and *Allies in Change*
- issue consultation on a revised complaints procedure by March 2002 and a new procedure to be in-place during 2002.

NHS Boards

- must work with local authority partners to ensure advocacy arrangements are in place and working effectively by December 2001
- must take account of and act on the recommendations made in *Fair for All* by March 2003
- must adopt agreed guidelines and recommendations for conducting surveys

Conclusions

This framework for change aims to support NHS staff and NHS organisations to develop services which reflect the needs and wishes of those who use them – a truly patient-focused service.

An additional £14million is available to be spent over the next 3 years to take forward the national initiatives described in this document. An initial allocation of the funding is

Building Capacity and Communications	£5m
Patient Information Initiative	£3m
Involvement	£3m
Responsiveness	£3m
Total	**£14m**

The change required to involve the people of Scotland in their NHS will not happen overnight but this framework lays down the stages that need to be taken to make NHSScotland responsive to the needs of service users. It will improve the quality of the service provided, provide a satisfying and rewarding environment for staff and improve the experience of patients using the NHS.

This money is for development and set ups costs. It does not include the monies currently used to support Local Health Councils. Money and resources currently used for this purpose will still be required. Health Boards are also expected to support and fund ongoing public involvement from within existing resource allocations.