

Framework ~ *December 2003*

Patient Focus and Public Involvement

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1. Introduction

NHS Quality Improvement Scotland (NHS QIS) was established to improve the quality of healthcare in Scotland by setting standards and monitoring performance, and by providing advice, guidance and support to NHSScotland on effective clinical care and service improvements.

Previously work to improve the quality of healthcare in Scotland had been carried out by a variety of different organisations. Since 1 January 2003 these organisations have been brought together as NHS QIS, to increase efficiency and to improve effectiveness by pooling resources and expertise. This new organisation is built on the expertise developed within the former: Clinical Resource and Audit Group, Clinical Standards Board for Scotland, Health Technology Board for Scotland, Nursing and Midwifery Practice Development Unit, and the Scottish Health Advisory Service. It also supports and works closely with the Scottish Intercollegiate Guidelines Network (SIGN) and the Scottish Medicines Consortium (SMC).

NHS QIS aims to:

- report to the public on the performance of NHSScotland against nationally agreed standards; and
- support NHSScotland in improving the quality of care and treatment it provides.

It will do this by working together with the public and those working in NHSScotland to:

- determine, share and promote consistent high quality healthcare across Scotland;
- set clinical and non-clinical standards for health;
- review and monitor performance through self-assessment by NHS organisations and external review;
- investigate serious service failures; and
- support NHS organisations to continuously improve the quality of their services by safeguarding high standards of care and creating working environments in which excellence in healthcare will flourish.

2. Principles of Patient Focus and Public Involvement

NHS QIS involves the public in its work in order to:

- improve the quality of health services in Scotland by ensuring that these are sensitive to the needs and preferences of patients;
- promote openness and transparency by enabling the public to review the quality of the NHS and be involved in NHS QIS processes;
- allow NHS QIS to learn from the experiences of patients and carers and gain an improved understanding of their needs and preferences; and
- focus NHS QIS work on patients and encourage public accountability by providing an essential complement to the expertise from health professionals and information from scientific literature.

Public involvement is recognised in the values that underpin NHS QIS work. Specifically these values are:

- patient and public focus: promoting a patient-focused NHS that is responsive to the views of the public;
- independence: reaching our own conclusions and communicating what we find;
- partnership: involving patients, carers and the public in all parts of our work;
- openness and transparency: promoting understanding of our work, explaining the rationale for our recommendations and conclusions, communicating in language and formats that are easily accessible; and
- sensitivity: recognising the needs, opinions and beliefs of individuals and organisations and respecting and encouraging diversity.

In the context of NHS QIS activities, the 'public' can be described in five overlapping groups. Each may want to be involved in a different way and to a different extent. Each time NHS QIS begins a new activity, it needs to think about who falls within these groups for the purpose of the activity and how best to involve them.

1. The general public:

People as citizens of Scotland and consumers who have used or who have the potential to use the services of NHSScotland, ie anyone in Scotland.

2. Patients (or users):

People who are using services or have recently used services.

3. The actively interested public:

People who take an active interest in services, particularly carers, and the family and friends of patients. This group may sometimes be integrated with 'patients'.

4. Patient interest groups:

People in organisations that can provide information about common and differing perspectives and needs of groups of patients.

5. People who may not get involved without particular recognition and a sensitive approach to their individual needs, background and circumstances:

For example, people from deprived or remote or rural communities; people with mental health problems; people with learning, physical or sensory disabilities; frail older people; children and young people; people who are lesbian, gay, bisexual or transgender; people who are carers; people for whom English is not a first language, people from ethnic minority communities; people who are travellers; people who are homeless; people in prison; or people seeking asylum.

NHS QIS will ensure that there is sufficient focus on the needs of diverse groups of people and compliance with relevant legislation and good practice. This will have implications for the way in which we involve people, how we provide information and support and the places we will meet people. There are also implications for training, particularly diversity and equality awareness.

3. The NHS QIS Patient Focus and Public Involvement Framework

This paper sets out the NHS QIS framework for achieving an effective partnership with the public. Their involvement is viewed as an integral and essential part of all aspects of NHS QIS activities, which will significantly contribute to the continuous improvement of health services in Scotland.

The framework has been developed in line with the four broad themes outlined in *Patient Focus Public Involvement* (Scottish Executive Health Department (SEHD) 2001). These build on the aims and key focus of *Our National Health: A Plan for Action, a Plan for Change* (SEHD 2000), which continue to be developed by *Partnership for Care* (SEHD 2003). Both of these health White Papers emphasise a culture change in the way that NHSScotland interacts with the people it serves and in the way that services are delivered to improve health. To achieve patient focused services, modern healthcare must work with the people it serves, look at services from a patient's point of view and be responsive to the needs of patients.

Partnership for Care describes public involvement in NHS QIS. It states that:

- *Patients have a central role in every aspect of the work of NHS Quality Improvement Scotland including the development of standards and the monitoring and review of compliance* (page 25); and
- *NHS Quality Improvement Scotland will ensure that its publications are accessible to patients and carers* (page 20).

The four broad overlapping themes of this framework are:

- (a) **Involvement** - ensuring that public involvement is an integral part of all NHS QIS activities to improve healthcare in Scotland.
- (b) **Building capacity and communications** - developing the ability to take effective action to improve services and to make sure that communications with people are clear, consistent and appropriate to promote public confidence.
- (c) **Responsiveness** - ensuring a range of opportunities for involvement are offered which are flexible and sensitive to the needs of individuals and communities, making it as easy as possible for people to participate fully.
- (d) **Patient information** - ensuring that people have the information that they require to be involved in decisions about their own care and to participate fully in the activities of NHS QIS.

3. The NHS QIS Patient Focus and Public Involvement Framework



Our work to support and develop a partnership with the public will be undertaken in line with NHS QIS values and the following principles:

- **resources** are defined and provided to enable participation eg information, training, independent support and advice;
- **feedback** is an integral part of the process and therefore people must be given information about the effectiveness of their involvement and the impact this has had on decisions taken; and
- any **limits** on the extent of public participation are negotiated, clearly stated and agreed by the NHS QIS Board.

4. The Actions We Will Take 2003-2005

NHS Quality Improvement Scotland will take the following approach to securing an effective partnership with the public:

(a) **Involvement:**

ensuring that public involvement is an integral part of all NHS QIS activities to improve healthcare in Scotland.

(b) **Building capacity and communications:**

developing the ability to take effective action to improve services and to make sure that communications with the public are clear, consistent and appropriate to promote public confidence.

(c) **Responsiveness:**

ensuring a range of opportunities for involvement are offered which are flexible and sensitive to the needs of individuals and communities, making it as easy as possible for people to participate fully.

(d) **Patient Information:**

ensuring that people have the information that they require to be involved in decisions about their own care and to participate fully in the activities of NHS QIS.

Further details of the approach that NHS QIS will take to securing an effective partnership with the public is set out in Appendix 1.

5. Future Developments

Over the next year a number of key developments will be built in to the Patient Focus and Public Involvement Framework. These include:

- the establishment of a new Scottish Health Council, as part of NHS QIS. The Scottish Health Council will: provide leadership to increase public involvement in NHSScotland; support the development of good practice in public involvement; and ensure that quality improvement is driven by the needs of patients and service users;
- NHS QIS being given the lead responsibility for improving patient safety in NHSScotland by ensuring the reporting of and learning from adverse events and near misses to enable changes to be made to improve the future safety of patients;
- the development of systems and procedures to investigate situations of serious failure of health services, in partnership with those who work in NHSScotland and the public; and
- NHS QIS working in partnership to support the development and delivery of safe and effective healthcare, such as new surgical procedures.

6. Being Open and Accountable

NHS QIS will evaluate the effectiveness of its approach by:

- collecting appropriate information about involvement activities;
- developing performance indicators to measure progress;
- monitoring progress against agreed performance indicators; and
- refining activities in the light of experience and feedback.

The outcome of evaluation will be reported in the NHS QIS annual report and published on its website.

7. Developing and Improving the Patient Focus and Public Involvement Framework

NHS QIS has developed this framework to set out its commitment and action plan to ensure that public involvement is an essential and integral part of all that it does. NHS QIS will involve the public in monitoring, evaluating and refining its framework as part of an ongoing process.



Appendix 1

The Actions We Will Take 2003-2005

(a) Theme:

Involvement ~ ensuring that public involvement is an integral part of all NHS QIS activities to improve healthcare in Scotland.

Action	Activities
1. Access	<p>1.1 Ensure venues for events and meetings have access for all and equipment for special needs as required.</p> <p>1.2 Ensure venues for events and meetings have good public transport links and access to car parking.</p> <p>1.3 Ensure that the time and location of meetings takes account of the needs and location in Scotland, of participants.</p> <p>1.4 Take account of accessibility issues and special needs requirements when planning NHS QIS premises.</p>

Performance Indicators

- 1.1.1 Information about participant's individual needs is actively sought in advance of events and meetings to aid planning.
- 1.1.2 An increase in the level of 'good' to 'very good' satisfaction with accessibility in organisational event questionnaires.
- 1.1.3 Monitoring of the increase in the number of people with special needs participating in events.
- 1.1.4 Develop and put into practice a pre-booking checklist to make sure that venues are accessible and catering is suitable.
- 1.2.1 Travel warrants are issued to participants as required, in advance of meetings.
- 1.2.2 Information is issued to participants in advance of meetings about claiming out of pocket expenses including travel, childcare and respite care.
- 1.3.1 Monitoring of the time and location of meetings and events.
- 1.3.2 Videoconference links to meetings and events are offered when possible, and their use monitored.
- 1.3.3. An increase in the range and type of opportunities for the public to get involved and have their say.
- 1.4.1 Satisfactory report by local disability groups or access committees and the Disability Rights Commission.
- 1.4.2 Action taken to improve access as recommended by above.

Performance Indicators

- 1.5.1 Growth in number of members of the public at consultation events.
- 1.5.2 Growth in number of responses to consultation from people without specialist training in field.
- 1.5.3 Evidence of the use of a circulation list for consultation documents which includes a wide variety of groups and individuals.
- 1.5.4 Project timelines indicating a minimum of 3 months for consultation.
- 1.5.5 All consultation documents to be available via the NHS QIS website and in an accessible format on request.
- 2.1.1 Criteria set and published for proposing topics.
- 2.1.2 Information published about how topics are prioritised and decisions made on which topics to pursue.
- 2.1.3 Record of growth in number of proposals received from the public or prepared in partnership with the public.
- 2.1.4 Monitoring of numbers of proposals received from the public which are taken forward in the work programme.
- 3.1.1 Participation of a minimum of two members of the public or suitable patient interest group representatives in working groups.
- 3.1.2 Information gathered about patients'/carers' needs and preferences at an early stage, particularly when identifying the issues to be addressed for different aspects of NHS QIS work eg standards development, health technology assessments.
- 3.1.3 Use of research evidence which takes full account of the experiences, needs and interests of patients, as well as clinical research evidence.
- 3.1.4 Participation of patient interest groups when developing project plans.
- 3.1.5 Submissions of evidence from patient interest groups.
- 3.1.6 Issues about the needs and preferences of the public highlighted to appropriate parts of NHSScotland, eg NHS Boards, NHS Education Scotland and NHS Health Scotland.

(a) Theme:

Involvement ~ ensuring that public involvement is an integral part of all NHS QIS activities to improve healthcare in Scotland (continued).

Action	Activities
	<p>3.2 Develop effective relationships with national organisations/groups that represent the public in order to reach local groups and networks.</p> <p>3.3 Develop effective links with NHS Boards' involvement initiatives to avoid duplication and to make effective use of established local involvement mechanisms.</p>



Performance Indicators
<p>3.2.1 Promotion of NHS QIS involvement opportunities by organisations/groups.</p> <p>3.2.2 Growth in participation in all aspects of NHS QIS work.</p> <p>3.3.1 All Designated Directors of Public Involvement will be kept informed of the NHS QIS work programme to facilitate partnership working.</p> <p>3.3.2 Shared working between NHS QIS and NHS Boards on suitable projects.</p>

(b) Theme:

Building capacity and communications ~ developing the ability to take effective action to improve services and to make sure that communications with the public are clear, consistent and appropriate to promote public confidence.

Action	Activities
4. Build capacity for involvement	<p>4.1 Continue to develop and refine the recruitment, training and support offered to non-NHS members of all working groups or teams.</p> <p>4.2 Promote a public involvement culture.</p>
5. Communications strategy	<p>5.1 Ensure that involving people is an integral part of a communication strategy including marketing of involvement opportunities, accessibility of language and format in publications and events, testing of publications with target audience, effective dissemination of information and transparency in recommendations and guidance.</p> <p>5.2 Ensure that members of the public are able to communicate in different ways which meet their needs and preferences including use of email and the Internet.</p> <p>5.3 Ensure those who have responded to consultation exercises receive feedback and a final document.</p>

Performance Indicators

- 4.1.1 Level of 'good' to 'very good' satisfaction results in team participant questionnaires obtained within first 2 years of operation.
- 4.1.2 On an annual basis, demonstrate that key training and support requirements identified by past and present participants are being responded to.
- 4.2.1 The training needs of staff and Board Members in public involvement values, skills and tools are assessed and training is provided to meet identified needs.
- 4.2.2 The training needs of working group/team chairpersons/leaders and members in public involvement values, skills and tools are assessed and training is provided to meet identified needs.
- 4.2.3 Promotion of organisational learning about public involvement at seminars and training days, demonstrated annually.
- 5.1.1 Establishment of a communications strategy in 2004.
- 5.1.2 Annual review of communications strategy.
- 5.1.3 Evaluation of communications strategy within first 3 years.
- 5.2.1 Promotion of website and email communications.
- 5.2.2. Monitoring of postal, telephone, e mail and internet inquiries to record change and respond to feedback on preferred communication methods.
- 5.2.3 Investigate installation of a textphone and publicise the number for use by people who are deaf.
- 5.3.1 Establish a protocol for responding to consultation comments, including timescale for response and information about the process for consideration of feedback and redrafting.

(c) Theme:

Responsiveness ~ ensuring a range of opportunities for involvement are offered which are flexible and sensitive to the needs of individuals and communities, making it as easy as possible for people to participate fully.

Action	Activities
<p>6. Promote a range of methods for securing patient focus and public involvement appropriate to the individual or group and the situation.</p>	<p>6.1 Provide information about consultation and publish documents in a range of formats.</p> <p>6.2 Identify groups underrepresented among public participants and develop strategies for overcoming barriers to their participation.</p> <p>6.3 Target opportunities to encourage participation of people who may not get involved without particular recognition and a sensitive approach to their individual needs, background and circumstances.</p>



Performance Indicators

- 6.1.1 Publications are made available by request on audio tape, electronically and in languages other than English.
- 6.1.2 Investigate the use of external validation of all NHS QIS publications to ensure plain language is used throughout.
- 6.1.3 Seek feedback from target audiences, to assess the quality and appropriateness of publications.
- 6.2.1 With the involvement of the public, particularly those from underrepresented groups, develop and publish a strategy and action plan to increase participation.
- 6.2.2 Identify and address barriers to participation that may exist with current methods of training, recruitment and support.
- 6.3.1 Working in partnership with patient interest groups, pilot techniques for identifying, involving and supporting people to promote inclusion and diversity, in a project starting in 2004.
- 6.3.2 Based on the pilot project, develop and implement a protocol for identifying, involving and supporting people to encourage their inclusion in NHS QIS projects.

(d) Theme:

Patient Information ~ ensuring that people have the information that they require to be involved in decisions about their own care and to participate fully in the activities of NHS QIS.

Action	Activities
<p>7. Contribute to the development of patient friendly plain language information outside of NHS QIS, to ensure that what we do is used to inform relevant patient information.</p> <p>8. Development of patient-friendly information within NHS QIS.</p>	<p>7.1 Develop mechanisms for ensuring evidence based health information is accurately and effectively included in patient information distributed by NHS Boards and promote its inclusion in patient guides produced by patient representative and voluntary groups.</p> <p>7.2 Provide guidance on communicating with patients in generic standards document and in other relevant publications.</p> <p>8.1 Develop opportunities for the public to be involved in producing publications in a user friendly accessible manner.</p> <p>8.2 Provide information about draft documents in a plain language, concise form to facilitate discussion, comments and feedback.</p> <p>8.3 Publish information explaining technical products for people without specialist training in the field.</p> <p>8.4 Evaluate appropriateness of publications with patients, carers and patient interest groups.</p>



Performance Indicators
7.1.1 Establishment of a protocol.
7.2.1 Publication and review of generic standards
7.2.2 Guidance on communicating with patients included in relevant publications.
8.1.1 Production of summaries of national overview reports on clinical services.
8.1.2 Production of a summary of standards for learning disability using text, pictures and symbols.
8.2.1 Evaluation report within first 2 years of operation.
8.2.2 Investigate the use of external validation of all NHS QIS publications (ie reports to the public) to ensure plain language is used throughout.
8.3.1 Evaluation report following the first 2 years of operation.
8.4.1 Evaluation report following the first 2 years of operation.

Our Commitment

Our work will be undertaken in line with the following values:

- **patient and public focus**
 - ~ promoting a patient-focused NHS that is responsive to the views of the public
- **independence**
 - ~ reaching our own conclusions and communicating what we find
- **partnership**
 - ~ involving patients, carers and the public in all parts of our work
 - ~ working with and supporting NHS staff in improving quality
 - ~ collaborating with other organisations such as public bodies, voluntary organisations and manufacturers to avoid duplication of effort
- **evidence-based**
 - ~ basing conclusions and recommendations on the best evidence available
- **openness and transparency**
 - ~ promoting understanding of our work
 - ~ explaining the rationale for our recommendations and conclusions
 - ~ communicating in language and formats that are easily accessible
- **quality assurance**
 - ~ aiming to focus our work on areas where significant improvements can be made
 - ~ ensuring that our work is subject to internal and external quality assurance and evaluation
- **professionalism**
 - ~ promoting excellence individually and as teams and ensuring value for money in the use of public resources (human and financial)
- **sensitivity**
 - ~ recognising the needs, opinions and beliefs of individuals and organisations and respecting and encouraging diversity

This document can be viewed on the NHS Quality Improvement Scotland website. It is also available, on request, from NHS Quality Improvement Scotland in the following formats:

- Electronic
- Audio cassette
- Large print

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