

A Participation Standard for the NHS in Scotland

Standard Document

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PATIENTS

PARTICIPATION

PUBLIC

Scottish Health Council



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1. Introduction and policy background

This document explains the policy background and purpose of the Participation Standard, how the Standard is structured, the assessment process, how improvement will be supported and how it was developed.

The NHS in Scotland aims to deliver the highest quality healthcare services to people in Scotland and through this to ensure that NHS Scotland is recognised as among the best in the world. In December 2007, the *Better Health, Better Care: Action Plan* was published by the Scottish Government, setting out an ambitious programme of work for the NHS in Scotland over five years. A central theme was to develop a “mutual NHS” which requires new ways of thinking about how health and healthcare are planned, delivered and evaluated.

“We need to move, over time, to a more inclusive relationship with the Scottish people; a relationship where patients and the public are affirmed as partners rather than recipients of care. We need to move towards an NHS that is truly publicly owned...where ownership and accountability is shared with the Scottish people and the staff of the NHS...where we think of the people of Scotland not just as consumers – with only rights – but as owners – with both rights and responsibilities”.

Better Health Better Care: Action Plan committed to the development of a Participation Standard to ensure that people are able to play their full part in a mutual NHS and to help bring about improvement in the quality of services.

In May 2010, the Scottish Government published the *Healthcare Quality Strategy for NHS Scotland* which commits to building on the achievements of *Better Health Better Care: Action Plan*. The strategy has three key quality ambitions:

- mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision making.
- there will be no avoidable injury or harm to people from healthcare they receive, and an appropriate, clean and safe environment will be provided for the delivery of healthcare services at all times.
- the most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit, and wasteful or harmful variation will be eradicated.

The *Healthcare Quality Strategy for NHS Scotland* also proposes to bring about “measurable improvement in the aspects of quality of care that patients their families and carers and those providing healthcare services see as really important” and to “put people at the heart of the NHS”.

'Participation', the involvement of patients, carers and communities in decisions about health services, has previously been referred to within the NHS as Patient Focus and Public Involvement. A general definition of patient focus is '*where people are respected, treated as individuals, and involved in their own care*'.¹ A general definition of public involvement is '*the practice of involving members of the public in the agenda setting, decision making, and policy forming activities of organisations/institutions responsible for policy development*'.² Within the context of the NHS 'participation' refers to Patient Focus and Public Involvement.

The Participation Standard builds on an agenda that has been developing over a number of years. To reflect the importance of participation, duties of public involvement and equal opportunities were placed on NHS Boards in the *NHS Reform (Scotland) Act 2004*. The Scottish Health Council was established in 2005 to ensure that NHS Boards deliver their participation (or Patient Focus and Public Involvement) responsibilities (see also part 6 below).

NHS Boards must routinely communicate with and involve the people and communities they serve to inform them about their plans and performance. This everyday involvement should follow the principles and practice set out in the Scottish Government guidance *Informing Engaging and Consulting People in Developing Health and Community Care Services*, and in *Communities Scotland's National Standards for Community Engagement* and its corresponding advice note - *Don't treat us all the same* - which advocates an inclusive approach to involvement.

In addition to this document a leaflet for the public explains what the Participation Standard is about, and what it will help to achieve.

¹ Patient Focus and Public Involvement Framework, Scottish Executive, 2005

² A Typology of Public Involvement Mechanisms, Gene Rowe and Lynn Frewer, Science Technology Human Values 2005, Sage Publications on behalf of Society for Social Studies of Science

2. Structure of the Standard and assessment process

Better Health, Better Care: Action Plan stated that establishment of a Participation Standard would enable the collection of systematic, comparable information on participation from across the NHS in Scotland.

The Standard sets out what NHS Boards need to do to make sure that people have a say, and a sense of ownership, both in their own care and in how health services are developed and delivered.

The Standard covers three aspects of participation which are set out in three **Standard Sections** described below.

1. Patient Focus – Care and services are provided in partnership with patients, treating individuals with dignity and respect, and are responsive to age, disability, gender, race, religion or belief, sexual orientation and transgender status.

2. Public Involvement – There is supported and effective involvement of people in service planning and improvement.

3. Corporate Governance – Robust corporate governance arrangements are in place for involving people, founded on mutuality, equality, diversity and human rights principles.

Format of the Standard

There are four documents associated with the Standard:

- The **Standard document** which sets out the criteria NHS Boards have to meet (this document).
- A **self-assessment framework** for NHS Boards to complete.
- A **guidance document** for NHS Boards on how to complete the self assessment.
- A **leaflet for the public** explaining the Standard and what it will help to achieve.

Within the Standard (see part 4 below) each section is set out in the same way:

- A **title**, which summarises the area on which the Standard Section focuses, for example ‘Standard Section 1 – Patient Focus’.
- This is followed by the **Standard Statement**, which explains the level of performance to be achieved.
- The **rationale** section provides the reasons why each Standard Section is considered to be important.

- Each Standard Statement is expanded in the section headed **criteria**, which describe the individual components within each Standard Section that NHS Boards will be assessed on.
- **References** are provided to demonstrate the policy or statutory basis for the criteria within each Standard Section.

The questions within the self-assessment framework are based on four levels of achievement which are outlined in the guidance document.

Developing the NHS Board is developing its arrangements

Implementing the NHS Board is implementing its arrangements

Evaluating the NHS Board is evaluating its arrangements

Improving the NHS Board is reviewing and continuously improving its arrangements

Self assessment against the Standard

The assessment of participation is an evolving process and in the financial year 2009/10 was based on NHS Boards producing an annual self assessment against locally agreed actions. These actions were agreed and assessed in partnership with local communities and the assessment was verified by the Scottish Health Council. For the Participation Standard NHS Boards will continue to complete a self assessment but using a self-assessment framework that will enable the collection of systematic, comparable information. This will include submission of supporting evidence. Suggestions of potential sources of evidence are listed in the self-assessment framework.

The Scottish Health Council will continue to work with patients, carers and communities to verify that these self assessments accurately reflect their experience.

All NHS Boards in Scotland will be asked to collect data to evidence the Participation Standard from 2010/11 and reviews to be conducted by the Scottish Health Council will begin in 2011/12.

Supporting Improvement

The Scottish Health Council will promote the sharing and evaluation of improvements in participation practice. It will do this by:

- sharing practice on its Evolving Practice website - http://www.scottishhealthcouncil.org/shc/pfpi/Case_Studies
- collating self-assessment information to show comparisons
- providing resources such as VOiCE (Visioning Outcomes in Community Engagement) and the Participation Toolkit
- working with local communities to build their capacity to participate

- bringing groups of staff together to network and share experiences
- developing the evidence base of what works by undertaking research and sharing the best examples of effective practice from the self assessments
- hosting national conferences to encourage sharing and dissemination of effective practice and discussion on key participation issues
- arranging good practice events for staff, the public and other stakeholders.

3. Development of the Participation Standard

A Participation Standard Development Group was established and first met in February 2009. It was agreed that the Standard should be developed in partnership, and build on existing standards, guidance, tools and policies to rationalise, integrate and align these where possible. The group comprised a range of stakeholders including Scottish Health Council, the public and voluntary sector, NHS Boards, and the Scottish Government. Some members of the development group also contributed to a writing group to develop the Standard.

A public consultation was conducted from June - August 2009 and involved people through a range of open meetings, focus groups and online feedback. Overall more than 200 people gave views either individually or as part of a group discussion.

The standard criteria and the three Standard Sections of patient focus, public involvement and governance were approved by the Scottish Government's Mutuality, Equality and Human Rights Board and by the Cabinet Secretary for Health and Wellbeing.

Further focus groups were carried out with NHS Boards in February 2010 to explore options for how the assessment process could work. The responses to the consultation and the analysis of these responses are available on the Scottish Health Council's website.

The Scottish Health Council has Equality Impact Assessed the Participation Standard and identified no adverse impact on equalities groups. A further impact assessment will be undertaken if the Standard requires to be changed following evaluation. A link to the Equality Impact Assessment can be found at www.scottishhealthcouncil.org

4. The Participation Standard

Standard Section 1 – Patient Focus

Standard Statement 1

Care and services are provided in partnership with patients, treating individuals with dignity and respect, and are responsive to age, disability, geographic location, gender, race, religion or belief, sexual orientation, socio-economic status.

Rationale

Understanding the wishes and needs of patients will lead to more effective and high quality healthcare.

The active participation of patients and, where appropriate, their carers in care and treatment planning makes a positive contribution to health outcomes and to their experience of care.

Services are more responsive to the diverse needs of patients or service users when planning is informed by their experiences and insights.

Equality Impact Assessments are carried out to ensure there is no adverse impact on particular groups of people and that everyone has equal opportunities to participate.

Criteria

- 1.1 NHS staff provide information and advice to patients in response to individual needs and preferences throughout the journey of care enabling and supporting informed patient choice and shared decision making.
- 1.2 Processes are in place to capture comments and complaints and include arrangements for ensuring feedback has an impact on service improvement.
- 1.3 People are able to access independent advice to support them in making a comment or complaint or obtaining information about health services.
- 1.4 Independent advocacy services are provided and developed in partnership with other agencies and the people who need them.
- 1.5 Individual need for independent advocacy is assessed, recorded and provided where necessary.
- 1.6 Support is in place to meet the needs of carers.

- 1.7 The NHS Board provides information about services in a range of formats, and has clear systems for responding to the specific communications needs of individuals.
- 1.8 People are treated with dignity and respect, in ways which recognise and respond to diverse cultural and social values.

References (links to these documents can be found in Section 5):

- *Healthcare Quality Strategy for NHS Scotland*, Scottish Government, 2010.
- *NHS Reform (Scotland) Act (2004)*
- *Human Rights Act 1998*
- Public sector duties contained within equalities legislation. Existing legislation will be superseded in time by the introduction of the Equality Act 2010.
- *(HDL) (2005) 15 Implementation of the NHS Complaints Procedure*, Scottish Executive, 2005
- *(HDL) (2006) 13 Patient Focus and Public Involvement: Independent Advice and Support Services*, Scottish Executive, 2006
- *Independent Advocacy: A Guide for Commissioners*, Scottish Independent Advocacy Alliance, 2010
- *HDL (2006) 22 NHS Carer Information Strategies: Minimum Requirements And Guidance On Implementation*, Scottish Executive, 2006

Standard Section 2 – Involving people in service planning and development

Standard Statement 2

There is supported and effective involvement of people in service planning and improvement.

Rationale

The delivery of ongoing improvements in the quality of healthcare services is greatly enhanced by the active involvement of patients or service users, carers, and others, including feedback on their experiences of the service.

Some people are unable to participate in service planning and delivery unless they have additional support. This may include people who have the greatest need of a service, but whose circumstances prevent them from making effective use of it.

Equality impact assessment helps to identify the range of potential barriers across the groups of people affected by a service or service change. People need support to express the barriers to their active participation, and to be involved in identifying measures to overcome them.

Positive experience of involvement in NHS services helps to create greater public confidence in the NHS Boards and in NHSScotland.

Criteria

The six elements of the Informing, Engaging, and Consulting Guidance are covered by the criteria: planning; informing; engaging; consulting; feedback; evaluation.

- 2.1 The people who may be affected by the proposed service development or change are identified and their support needs assessed (planning).
- 2.2 The people who may be affected by the proposed service development or change are provided with relevant information and other appropriate communication aids that meet identified support needs (informing).
- 2.3 The people who may be affected by a proposed service development or change take part in developing, and appraising options, and are consulted appropriately (engaging and consulting).
- 2.4 Feedback is provided to the people involved on decisions made and how their views are taken into account (feedback).
- 2.5 Evaluation of the involvement is planned and carried out on an ongoing basis (evaluation).

References:

- *NHS Reform (Scotland) Act (2004)*
- *Healthcare Quality Strategy for NHS Scotland*, Scottish Government 2010
- *CEL10 (2008) Refreshed Strategy for Volunteering in the NHS*, Scottish Government 2008
- *CEL 4 (2010) Informing, Engaging Consulting People in Developing Health and Community Care Services*, Scottish Government 2010
- *Human Rights Act 1998*
- Public sector duties contained within equalities legislation. Existing legislation will be superseded in time by the introduction of the Equality Act 2010.

Standard Section 3 – Corporate governance of participation

Standard Statement

Robust corporate governance arrangements are in place for involving people, founded on mutuality, equality, diversity and human rights principles.

Rationale

NHS Board members have overall responsibility for the quality of the Board's services, and for the quality of participation in service design and delivery.

NHS Board members are responsible for ensuring that their organisation meets the statutory duties in relation to participation and equalities and for promoting good practice by providing leadership as well as challenge.

NHS Boards are required to have in place structures and systems which manage performance across their organisation, and which provide assurance to Board members of the quality of participation in services.

The actions of NHS Boards are open to public scrutiny. Demonstrating a culture in which participation is encouraged, supported, and valued can be a positive way of developing or reinforcing public confidence in the Board's staff and services.

Criteria

- 3.1 The NHS Board is assured that systems and processes are in place to enable it to meet statutory requirements in relation to the participation agenda.
- 3.2 The public feed into governance and decision-making arrangements.
- 3.3 The NHS Board is assured that a culture is encouraged throughout the organisation where participation forms part of the day-to-day planning and delivery of services.

References:

- *NHS Reform (Scotland) Act (2004)*
- *Healthcare Quality Strategy for NHS Scotland*, Scottish Government, 2010
- *CEL 4 (2010) Informing, Engaging Consulting People in Developing Health and Community Care Services*, Scottish Government, 2010

- *The Community Health Partnerships (Scotland) Regulations 2004, and Guidance*, Scottish Executive, 2004
- *CEL 10 (2008) Refreshed Strategy for Volunteering in the NHS*, Scottish Government, 2008
- *The Good Governance Standards for Public Services*, Chartered Institute of Public Finance and Accountancy / Office for Public Management, 2004
- Public sector duties contained within equalities legislation. Existing legislation will be superseded in time by the introduction of the Equality Act 2010.

5. Further reading

Strategy documents

Partnership for Care, Scotland's White Paper, Scottish Executive, 2003
www.scotland.gov.uk/library5/health/pfcs-00.asp

NHS Reform (Scotland) Act (2004)
Duties of Public Involvement and Equal Opportunity placed on NHS Boards
http://www.opsi.gov.uk/legislation/scotland/acts2004/asp_20040007_en_1

The Community Health Partnerships (Scotland) Regulations 2004, and Guidance, Scottish Executive, 2004
<http://www.sehd.scot.nhs.uk/chp/guidance.htm>

Building a health service fit for the future, (Kerr Report – section 7), Scottish Executive, 2005
<http://www.scotland.gov.uk/Publications/2005/05/23141307/13261>

Delivering for Health, Scottish Executive, 2005
<http://www.scotland.gov.uk/Publications/2005/11/02102635/26356>

Better Health Better Care: Action Plan, Scottish Government, 2007
<http://www.scotland.gov.uk/Resource/Doc/206458/0054871.pdf>

Clinical Governance and Risk Management

Clinical Governance and Risk Management Standards, NHS Quality Improvement Scotland, 2005
<http://www.nhshealthquality.org/nhsqis/2762.html>

The Good Governance Standards for Public Services, Chartered Institute of Public Finance and Accountancy / Office for Public Management, 2004
http://www.cipfa.org.uk/pt/download/governance_standard.pdf

Community Engagement

Community Health Partnership: Involving People Advice Notes, Scottish Executive, 2004
<http://www.sehd.scot.nhs.uk/chp/PPF%20advice%20note%20-%20PDF.pdf>

The National Standards for Community Engagement, Communities Scotland, 2005
<http://www.scdc.org.uk/national-standards-community-engagement/>

VOiCE (Visioning Outcomes in Community Engagement), The Scottish Community Development Centre, 2008
<http://www.scdc.org.uk/voice/>

CEL 4 (2010) Informing Engaging and Consulting People in Developing Health and Community Care Services, 2010

http://www.sehd.scot.nhs.uk/mels/CEL2010_04.pdf

Complaints, Advocacy, and Carers

HDL (2005) 15 Implementation of the new NHS Complaints Procedure, Scottish Executive, 2005

http://www.sehd.scot.nhs.uk/mels/HDL2005_15.pdf

HDL (2006) 13 Patient Focus and Public Involvement. Independent Advice and Support Services, Scottish Executive, 2005

http://www.sehd.scot.nhs.uk/mels/hdl2006_13.pdf

Independent Advocacy: A Guide for Commissioners of Advocacy, Scottish Independent Advocacy Alliance, 2010

<http://www.siaa.org.uk/content/view/19/36/>

Equalities

Equality Act 2010

Public sector duties contained within equalities legislation. Existing legislation will be superseded in time by the introduction of the Equality Act 2010. Legislation and good practice guidance can be accessed on the website of the Equality and Human Rights Commission.

<http://www.equalityhumanrights.com>

Human Rights Act 1998

http://www.opsi.gov.uk/acts/acts1998/ukpga_19980042_en_1

Patient Rights Bill

<http://www.scottish.parliament.uk/s3/bills/42-PatientRights/b42s3-introd.pdf>

Checking for Change: A building blocks approach to race equality in health

<http://www.checkingforchange.org.uk/aboutus/>

Patient Focus

Better Together - The Patient Experience Programme

<http://www.bettertogetherscotland.com/bettertogetherscotland/26.html>

Volunteering

CEL 10 (2009) – Refreshed Strategy for Volunteering in the NHS in Scotland

http://www.sehd.scot.nhs.uk/mels/CEL2008_10.pdf

6. About the Scottish Health Council

What is the Scottish Health Council?

The Scottish Health Council's role is to improve how the NHS in Scotland involves people in decisions about health services.

Its aim is to improve how the NHS:

- listens to the public
- values their views and experiences
- respects them as individuals; and
- involves them in planning and developing health services.

The Scottish Health Council also provides support services for Independent Scrutiny Panels that are established by the Scottish Government to consider proposals for major changes to local health services.

In addition to a national office in Glasgow, there are local offices in each NHS Board area.

What does the Scottish Health Council do?

The Scottish Health Council helps to make sure people can have a say in the NHS by:

- supporting NHS Boards to share good practice, exchange ideas and develop new approaches on how to involve people in health services
- assessing and reporting on how well NHS Boards involve people in the development of services, and
- working with NHS staff and communities to improve how patients, carers and the public are involved in health services.

What is Patient Focus and Public Involvement?

NHS Boards have a responsibility to focus on the needs of patients by listening to them and responding to their needs, and to involve people in the planning and development of health services. This is sometimes called 'Patient Focus and Public Involvement'.

Patient Focus and Public Involvement is a priority for all NHS Boards and a key aspect of the Scottish Government's plans to deliver a health service that:

- respects people and treats them as individuals; providing information and support so that they can be fully involved in decisions about their own care and treatment
- involves patients and the public in improving the quality of healthcare, identifying local priorities, and influencing service changes.

What should NHS Boards be doing?

All NHS Boards need to demonstrate that they are listening and responding to the needs of people using health services. There are many different ways that they can do this. For example, most NHS Boards have Public Partnership Forums to give members of the public an opportunity to input their views on health services.

Everyone in Scotland should have fair access to health services and be treated with dignity and respect whatever their individual circumstances may be. NHS Boards should identify and respond to the needs of individual patients and carers. This would include, for example, making information available in other languages and formats for people who need them. NHS Boards should also involve communities in planning and developing services, for example, by holding public events to discuss proposals for changes to services.

How can you find out more about the Scottish Health Council?

You can find out more about what the Scottish Health Council does by visiting its website: www.scottishhealthcouncil.org

Contact address: Scottish Health Council
National Office
Delta House
50 West Nile Street
Glasgow G1 2NP

Telephone: 0141 241 6308

Fax: 0141 221 2529

There is a local office in each NHS Board area. To find contact details for the nearest local office, see the website at www.scottishhealthcouncil.org or telephone the national office on the number above.

The Scottish Health Council wishes to express its gratitude to the following groups of people, all of whom contributed to the development of the Participation Standard:

Members of the public and NHS Board representatives who took part in focus groups

Public Partnership Forums representatives

Patient, public, community and voluntary sector groups

Members of the Standard Development Group

NHS Board representatives who were members of the Standard Implementation Group from NHS Borders, NHS Quality Improvement Scotland, NHS 24, NHS Highland, NHS Lothian, NHS Greater Glasgow and Clyde, and NHS Fife

Scottish Government Health Directorate representatives

Better Together Programme representatives

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Scottish Health Council

National Office

Delta House

50 West Nile Street

Glasgow G1 2NP

Phone: 0141 241 6308

Email: enquiries@scottishhealthcouncil.org

Website: www.scottishhealthcouncil.org