Public involvement structures for the NHS

A pre-consultation
About the Scottish Consumer Council

The Scottish Consumer Council (SCC) was set up by government in 1975. Our purpose is to promote the interests of consumers in Scotland, with particular regard to those people who experience disadvantage in society. While producers of goods and services are usually well-organised and articulate when protecting their own interests, individual consumers very often are not. The people whose interests we represent are consumers of all kinds: they may be patients, tenants, parents, solicitors' clients, public transport users, or simply shoppers in a supermarket.

Consumers benefit from efficient and effective services in the public and private sectors. Service-providers benefit from discriminating consumers. A balanced partnership between the two is essential and the SCC seeks to develop this partnership by:

- carrying out research into consumer issues and concerns;
- informing key policy and decision-makers about consumer concerns and issues;
- influencing key policy and decision-making processes;
- informing and raising awareness among consumers.

The SCC is part of the National Consumer Council (NCC) and is sponsored by the Department of Trade and Industry. The SCC’s Chairman and Council members are appointed by the Secretary of State for Trade and Industry in consultation with the Secretary of State for Scotland. Future appointments will be in consultation with the First Minister. Martyn Evans, the SCC’s Director, leads the staff team.

Please check our web site at www.scotconsumer.org.uk for news about our publications.

Scottish Consumer Council
Royal Exchange House
100 Queen Street
Glasgow G1 3DN
Telephone 0141 226 5261
Facsimile 0141 221 0731
www.scotconsumer.org.uk

The SCC assesses the consumer perspective in any situation by analysing the position of consumers against a set of consumer principles.

These are:

ACCESS
Can consumers actually get the goods or services they need or want?

CHOICE
Can consumers affect the way the goods and services are provided through their own choice?

INFORMATION
Do consumers have the information they need, presented in the way they want, to make informed choices?

REDRESS
If something goes wrong, can it be put right?

SAFETY
Are standards as high as they can reasonably be?

FAIRNESS
Are consumers subject to arbitrary discrimination for reasons unconnected with their characteristics as consumers?

REPRESENTATION
If consumers cannot affect what is provided through their own choices, are there other effective means for their views to be represented?

We can often make our publications available in braille or large print, on audio tape or computer disk. Please contact us for details.

We are grateful to all of those who assisted us in the preparation of this report.

The views expressed in this report are not necessarily those of the Scottish Consumer Council unless specifically stated.
The Scottish Executive Health Department issued a paper in December 2001 entitled Patient Focus and Public Involvement containing outline policy ideas for re-shaping structures to support public involvement in the NHS including health councils. In order to inform these proposals the Health Department commissioned the Scottish Consumer Council and Scottish Health Feedback to undertake a pre-consultation to gather opinions on the form of these proposals.

The pre-consultation took the form of 21 meetings, which were conducted by experienced neutral facilitators. They were held with:

- NHS Board Chairs and Chief Executives
- Health Council Chairs and Chief Officers
- Representatives of voluntary organisations at a national level
- Organisations that support people in their interactions with the NHS with health and community care services at a local level throughout Scotland.

All participants received a briefing paper prior to attending meetings, which summarised the relevant proposals. This report aims to summarise the findings of the consultation and to set out the implications for the drafting of the consultation document.

Responsibility for public involvement

There were a number of assumptions underlying the policy proposals in Patient Focus and Public Involvement. There was broad agreement by all groups that the primary responsibility of involving patients should lie with the NHS Boards. There was a view that it must be made clear that this responsibility extends to trusts, LHCCs and practices. It should also be made evident that this is expected to result in changes in services, i.e. the NHS must not only listen to patients but act upon what it hears.
Views about local health councils

There was agreement from those who were familiar with health councils that their credibility was undermined because they were not seen as sufficiently independent of health boards. Creating a system which was genuinely independent was agreed to be a positive step. The consultation should ask about how such independence could be achieved in practice, which clearly relates to how the SHC is governed, and who it is accountable to.

Health councils were seen as gaining from being locally based and this was seen as a great strength, which should not be lost in any new proposals.

Health councils and NHS Boards agreed that under the present structure health councils have a range of functions, which are carried out to varying extents by different councils. This variation was not necessarily seen as a weakness although more consistency might help the public have a better understanding of its role. It was agreed that some functions should be core and common to all health councils.

There was broad agreement that some change was desirable.

Proposed new functions

There were three main functions proposed for the new structure. They were:

• Development,
• Assessment and
• Feedback.
Whilst these were seen as appropriate functions for the new organisation there were many comments on how these roles might be discharged and some suggestions as to how these roles might be widened or added to, to benefit patients.

**Development**

Under discussions about development, there were comments about the need for the NHS itself to develop its capacity to undertake public involvement. Whilst noted, this is already being examined as a separate issue.

Key comments about the development function included the need to recognise the scale of the task, to ensure that it is properly resourced and to ensure that the development work undertaken by health councils worked with rather than duplicated the work of other initiatives such as community planning.

**Assessment**

For many, the assessment role meant monitoring that the public involvement process had made an impact on services as well as ensuring that appropriate public involvement mechanisms were in place. For some this implied that some monitoring of service delivery should be allowed for. There were concerns expressed by a few that health councils' current powers to visit health premises would be lost.

Many participants also spoke of the need for the new structures to have some clout to ensure that patients' views were acted upon.

As with the development function, there were concerns about the demarcation between the proposed new structures and other organisations undertaking similar work for example the Clinical Standards Board for Scotland (CSBS) and the Scottish Health Advisory
Service (SHAS). It was important not to duplicate the work of others.

The key issues raised in relation to the assessment function were:

- There was a resistance to narrowing of functions and dilution of role of watchdog
- The importance of assessing not only public involvement but the impact of that involvement on the service itself
- The relationship between the proposed Scottish Health Council (SHC) and CSBS in their respective assessment roles
- The extent of the powers that the SHC should have (for example those who looked for a watchdog role sought power to monitor services, to request and receive information and to be consulted on service change).

**Feedback**

The main concern in relation to the feedback function focussed on the role of the new structures in relation to complaints and whether its role would also extend to representing patients' views. Given that the proposed structure places such an emphasis on working with and developing the capacity of organisations there were concerns that the individual might get left out. It was seen as essential that any new bodies should provide an accessible and effective route for individuals to get their views across. This was clearly intertwined with any role they had in supporting complaints. Again the impact of feedback was discussed, with the point being made that it must bring about an improvement in services to match the needs of patients.

The view was expressed that the feedback role should be expanded to allow the new bodies to be proactive and raise issues of public concern which might not have a corresponding local user organisation, for example accident and emergency services or out of hours services.
General comment on functions

There was a lack of clarity about the role and functions of the proposed new bodies. In order to get useful feedback from the consultation process it will be important to be very clear about the nature and role of the new bodies and how these differ from existing structures.

The pre-consultation was hampered by a lack of knowledge of existing health councils’ roles and functions. It is therefore recommended that the consultation document presents the existing health council functions alongside an outline of how these functions would be undertaken under the proposed structure.

Health councils in Scotland have agreed a common set of core objectives that could be used to structure the discussion in the consultation document. These are:

- To act as the voice of patients / public in the health council area
- To influence health gain by contributing to a patient-centred health service
- To monitor health services
- To provide and develop information and advice strategies
- To manage health council resources
- To contribute to the national voice for patients and the public in health matters.

It is important that the consultation document explains how each of these objectives would be achieved in any new structural arrangement.

The pre-consultation raised issues of potential conflict of interest in relation to the different roles that the proposed new structures would have. For example, between the function of supporting and developing public involvement and the scrutiny of how well public involvement has
been carried out or between supporting public involvement and actually carrying out public involvement activities.

The consultation should explore how those consulted feel about these possible conflicts of interest and how they could most effectively be reduced.

**Complaints**

The pre-consultation did not deal with complaints directly and so there was a tendency to fit it within one of the three functions, most typically the “feedback” function.

There were mixed views on the extent to which the local offices of the proposed Scottish Health Council should get involved in complaints and how far that involvement should go. It was thought it would be very easy for the organisation to get bogged down in complaints and become a reactive organisation instead of gathering views and taking a proactive role in improving services.

Again the relationship of the proposed Scottish Health Council to other organisations involved with assisting people with their complaints needs to be addressed and also its relationship to advocacy services. It was also recognised that complaints were unlikely to remain solely within the health field and can extend to social work/community care.

There was a strong agreement that the proposed SHC at national level should have a role in relation to complaints. Its role should be strategic, monitoring complaints handling and procedures. Health councils already had much experience in the complaints process and it was important that these skills were not lost to the public.
It is important to make it clear in the consultation document what is intended to happen in relation to complaints and advocacy. In particular it should be made clear what the intention is in relation to:

- Where a patient or member of the public can expect to get information about how to make a comment on a service and how to make a complaint.
- Where a patient or member of the public can get support in preparing and pursuing a complaint.
- Who will have the primary responsibility for providing such support.
- Who will be in a position to monitor complaints data and to ensure that complaints are being properly handled by the NHS.
- How the system will allow for complaints which cross the boundaries between health and social care.

The consultation document should also make it clear where the responsibility for providing advocacy rests and how members of the public can access such services.

Proposals will need to take account of current work being undertaken in relation to the NHS complaints procedure, as well as the work associated with Patient Focus and Public Involvement.

**Proposed new bodies**

There was broad agreement with the proposal for a national body with local offices. There was less agreement concerning the proposed Health Service User Forums and it was on this final part of the structure that discussion tended to focus.
Scottish Health Council

There were concerns that a move to a national body might prejudice the grassroots structure and introduce more bureaucracy. The balance of opinion was that any new structure should be rooted in local concerns. Whilst a more consistent approach had its advantages there could be tension between control from a national body and the need for local flexibility.

The powers that the proposed Scottish Health Council should have were discussed at meetings. There was a common theme that it must have the power to have some sanction if the NHS did not respond to the views of patients. It should also have the power to raise matters of public concern especially to raise those issues which had no organisation focusing on it, such as in relation to acute conditions or those attending A and E departments. It should be consulted on proposed service changes and should have the power to meet with NHS staff, ask questions and be provided with information. It should regularly receive information on public involvement activities and their outcomes.

In relation to the Performance Assessment Framework through which NHS boards are held to account by the Scottish Executive Health Department, the Scottish Health Council would expect to attend meetings as part of the assessment process and comment on the extent and quality of the Board's public involvement activity. It could also develop tools to help with the assessment and evaluation of public involvement. Such tools should also extend to the impact public involvement has made on services.
Local offices of the Scottish Health Council

The need for a local presence of the Scottish Health Council was felt to be more important in rural areas and there were suggestions of organising local offices of health councils at LHCC level, at local authority level or in the areas covered by Community Care Forums.

It should be a matter of concern that there was a lack of knowledge about existing health councils amongst those working with voluntary organisations and with the public. Those consulted considered that any new structure should have a high degree of visibility in the public eye to ensure it operated effectively and the public should understand what it was there to do.

Health service user forums

The main concerns lay in the proposals for health service user forums. Although there was strong support for good connections with local concerns and issues, and for control to lie at grassroots level those consulted remained to be convinced of the proposed forums.

It was thought that there could be such a large number of organisations involved that it would be too large to be manageable.

There were further fears of forums being dominated by minority interests or by paid workers within the voluntary sector and not by service users. Forums should work with and not duplicate the work of existing organisations and some felt that their remit should extend to social care as well as health. There are other forums in place, with community care forums being mentioned frequently in the pre-consultation. There were concerns of volunteer fatigue if yet another forum were established. The loyalty of those attending the forums would
tend to be to their own organisations.

It was seen as important that whatever structure was in place had the capacity to respond to local needs. Those consulted welcomed the independence of the forums from health boards. There was a positive response to the idea of involving people from the grassroots but there was no vision of how this would work in practice.

It was not clear how the link between a professionally driven SHC and a grassroots based health service user forum might work in practice. Despite this there was strong support for any new bodies to be firmly rooted in local concerns.

The consultation document should spell out how this might work in practice and how the local offices of the proposed health council would relate to the local community. For example, local offices could be required to:

- Have an advisory group drawn from local people, patient groups, community organisations, and other forums (such as community care forums, patient councils or forums)
- Draw up and work to an annual workplan which should be approved by the advisory group
- Demonstrate in all their work that they have involved and co-operated with a wide range of local interests
- Work with existing networks and forums
Governance

There was little discussion in relation to how the proposed Scottish Health Council should be governed. Some proposed that members of the governing body should be elected, but there were no suggestions about how such an election would work, or who would be eligible for election. There were concerns about the current means of appointing health council members, and there were concerns that whatever method of finding members of the governing body was used, there would be a tendency for certain types of people to be over-represented. This included those involved with organisations representing chronic conditions. There was also recognised to be a need to have a geographical and demographic spread.

Legitimacy

This is linked to the issue of governance though not identical to it. Legitimacy may be derived from a direct election process, but where appointed, bodies may seek legitimacy for what they do through the way in which they operate.

The legitimacy of the local offices will be affected by the extent to which they engage with their local communities. The following issues need to be addressed in the consultation document, either by stating the Executive's preferred policy and asking for comment, or by presenting clear options and inviting views on these.

• The governance of the Scottish Health Council - will it be an NDPB with appointed members, or will there be a mixture of appointment and nomination of members from particular constituencies?
• Accountability of the SHC - should it be to the minister, the Scottish Executive, the Health and Community Care Committee or to the public?

• Independence of the SHC. The consultation should ask about how such independence can be achieved in practice, which clearly relates to how the SHC is governed, and who it is accountable to.

• Number of local offices of the SHC. There was broad agreement in the pre-consultation that there should not be less than one local office in each health board area, but some of those consulted, particularly in rural areas, thought that there should be more than one. The consultation should explore this further.

• Nature and status of local health service user forums. This proved to be a particularly difficult area in the consultation, and there will need to be much greater clarity about the role of these bodies. One possibility would be for the consultation to present this issue in the context of achieving legitimacy for the local offices of the health council, and to outline the ways in which local offices could do this, as discussed above.

• An indication of resourcing and staffing levels in all three organisations

Content and style of the consultation

The implications for the consultation in terms of the content and style are as follows.

The wider context

Those wishing to respond to the consultation document must have sufficient background to set the proposals in context, as well as information on other initiatives having an impact on how the NHS turns itself into a patient centred organisation. This includes planned
improvements in information provision; how the NHS proposes to develop the capacity of its staff to engage with the public; current work being undertaken by the Involving People team etc.

There must also be explicit reference to other bodies e.g. the Clinical Standards Board for Scotland, engaged in parallel agendas and the consultation document should set out the broader picture making it clear what the proposed role and function of each organisation is.

**Language**

It is important to use language which most clearly expresses the intentions behind the proposals. There was some ambiguity about the words “feedback”, “development” and “assessment” with those participating in the pre-consultation taking different meanings from the words used. It needs to be made clear exactly what is being proposed.

It is noted that the word “representation” was missing from the pre-consultation and whilst the general move is away from dialogue taking place via intermediaries, it must be acknowledged that there may remain some circumstances where representation is required. It is important to consider how such representatives are selected and prepared for this role. It is suggested that the issue of representation is addressed explicitly within the consultation document.

There were further difficulties with the continued use of the term, “health council” in the pre-consultation document which led some to believe that no major change was intended. It is important that the consultation document makes it clear what change is intended.
Scope and extent of consultation

It is important the consultation:

- Is over an acceptable period of time
- Is targeted at as many relevant groups as possible
- Engages proactively with groups, which might otherwise be overlooked in a formal written consultation.

Feedback

There is some cynicism that the pre-consultation might have little impact. The consultation should acknowledge points that were raised in the pre-consultation.

Transition issues

There should be some indication in the consultation document about what will happen to existing staff, in terms of redeployment and training for any additional skills required.

Public profile

The public profile of any proposed structure must be considered. The importance of its recognition by the public will be determined by the role that it is to play. An organisation focussed on development does not need a particularly high profile whilst a watchdog role would require a much higher profile.

The name of the proposed body is related to the role of the new organisation and the image that it wishes to convey. For example, “Healthwatch” has connotations of a watchdog whilst “Healthvoice”
suggests a focus on communication. The Executive will need to consider whether to include a question about this in the consultation, or whether to indicate its attitude to the profile of the new bodies.

The pre-consultation mentioned both the need to take into account links to other services such as social care, education and housing and that any proposed structures should build on and not duplicate existing structures in social and community care spheres.
Conclusion

In conclusion there was broad support for change and a general agreement with most of the assumptions underlying the proposals for change. There remain some key issues where there was less agreement including the best structure to provide grassroots input. There were also several concerns raised about the proposals. These are listed below.

Functions

There was a significant body of opinion that the functions of the new structures should not be limited to public involvement activity, but should include the following:

- monitoring the impact of public involvement in changed or improved services
- supporting those who wish to make a complaint
- proactively raising issues of concern

The first bullet point above is a particularly important one, which was consistently mentioned throughout the pre-consultation, and must be fully taken account of in the final consultation document.

Manner of operation

The following were considered to be important in the way the proposed new structure operated:

- being independent
- having a consistent approach with local flexibility to address local concerns
- being visible to and understood by the public
- being accessible to individuals as well as organisations
- being accessible to those with disabilities
• being controlled at a local level
• making links with community care, community planning, and the Joint Futures agenda, without creating duplication or creating a confusing overlap
• having links with advocacy services and others who assist with complaints
• having links with other bodies who also have an assessment role
• providing feedback to those who provide their views

Concerns

There were concerns about the following:

• the danger of increased bureaucracy
• tension between national and local organisations in the proposed new structure
• forums being unwieldy and prone to minority interests dominating
• forums being dominated by paid workers and not health service users
• volunteer fatigue
• losing the experience of existing staff - transition issues
• being adequately resourced and recognising the scale of the task
• extent of involvement in complaints process