Public involvement structures for the NHS

A pre-consultation
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- informing key policy and decision-makers about consumer concerns and issues;
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Scottish Consumer Council
Royal Exchange House
100 Queen Street
Glasgow    G1 3DN
Telephone 0141 226 5261
Facsimile 0141 221 0731
www.scotconsumer.org.uk

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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?

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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.

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We would like to thank all those who took part in this pre-consultation exercise, and also those who helped to organise the focus groups. Staff at Scottish Health Feedback organised all the local groups, and Susan Browne, Researcher at the Scottish Consumer Council, organised the groups with national voluntary organisations. The Scottish Executive Health Department helped us to access the views of chairs and chief executives of NHS boards, as well as health council chairs and chief officers. Details of participants in the local groups is included in an appendix to the report.

This report is produced jointly by the Scottish Consumer Council and Scottish Health Feedback. The main contributors to this final report are:

Lyn Jones, Scottish Health Feedback
Carole Millar, Carole Millar Research
Martyn Evans, Scottish Consumer Council
Liz Macdonald, Scottish Consumer Council

The focus groups were facilitated by:

Lyn Jones, Scottish Health Feedback
Carole Millar, Carole Millar Research
Alan Ross, independent consultant
Summary

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.

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 lies 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.

There was also agreement from those who were familiar enough with health councils that their credibility was undermined because they were not seen as sufficiently independent of health boards. Although rare there
had been examples of interference and a formal independence was agreed as a positive step.

**VIEWS ABOUT LOCAL HEALTH COUNCILS**

Currently 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.

Current health councils and NHS boards agreed that under the current structure health councils have a range of functions, which are carried out to varying extents by different councils. Once again this variation was not necessarily seen as a weakness although more consistency might help the public create 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 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 CSBS and SHAS. It was important not to duplicate the work of others. There were also comments that the assessment role might be in conflict with the other two roles of development and feedback and there may be an element of assessing its own performance.
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 may 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 very intertwined with what 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 may not have a corresponding local user organisation, for example accident and emergency services or out of hours services.

Complaints
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.

**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 those with 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.

There were a number of suggestions as to whom SHC should be accountable. They were:

- The Minister for Health
- The Scottish Executive - but retaining links to the Minister.
- Health and Community Care Committee
- The public

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.

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 is 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 them being dominated by minority interests or by paid workers within the voluntary sector and not by service users. They too must work with and not duplicate the work of existing organisations and some felt that its 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 idea of independence of the organisation 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.
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

In addition no clear views were expressed on how the new bodies should be governed.

**Concerns**
There were concerns about the following:

• increased bureaucracy
• tension between national and local arms of the Scottish Health Council
• 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

These are the main issues that should be addressed in the forthcoming consultation document.
Background

POLICY DEVELOPMENT

The Scottish Executive Health Department issued a paper in December 2001 entitled Patient Focus and Public Involvement, outlining intentions to support, encourage and increase opportunities for patients and the public to engage constructively with the Health Service.

This took forward the proposals in Chapter 5 of Our National Health: A plan for action, a plan for change. One part of it described outline policy ideas for re-shaping structures to support public involvement in the NHS in Scotland.

Later in 2002 more detailed policy proposals will be set out in a formal consultation paper which will be circulated widely for comment. In order to inform those proposals, the Department wished first to gather views across Scotland on the outline policy ideas and how they might be put into practice. Scottish Health Feedback and the Scottish Consumer Council were invited to carry out this “pre-consultation” for the Department. The pre-consultation concentrated on the issues raised by one specific part of the paper Patient Focus and Public Involvement—the section headed Local Health Councils.

THE PRE-CONSULTATION PROCESS

Discussion meetings conducted by experienced, neutral facilitators 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 health and community care services around Scotland.
There was one meeting of the last category in each health board area.

**STRUCTURE OF THIS REPORT**

All participants in the discussion groups were sent a briefing paper in advance. This briefing paper was based closely on the paper *Patient Focus and Public Involvement*. This first set out the details of the consultation process itself, then summarised some of the assumptions on which the proposed changes were predicated. Then the main functions and structures for the proposed new arrangements were set out; and finally a list of policy questions left open in the paper *Patient Focus and Public Involvement* was presented. Discussions in the groups took place under these headings, with flexibility to allow for the interests expressed. This report uses the same headings to report the views of participants, after first recording some facts about the process itself.
DISCUSSION GROUPS

NHS Board Chairs and Chief Executives

There was one meeting held with chief executives of NHS boards and trusts and one with health board chairs. Each of the discussions were held as part of the agenda of a regular series of meetings with about 40-45 minutes being allocated to the discussion.

There were between 40 and 50 attendees at the chief executives meeting and about 20 at the health board chairs meeting.

Discussion was limited by the size of the groups and the time available and consequently tended to dwell more on general principles and wider issues.

In addition it was not possible for all who attended those meetings to contribute and the report inevitably draws only on those views expressed.

Health Council Chairs and Chief Officers

One discussion group was held with health council chairs and members of the Executive of the Scottish Association of Health Councils (the chairs/ Members group). A second group was held with health council chief officers.

Organisations that support people in their interactions with health and community care services around Scotland.

The aim was to include as broad a cross-section of health-related interests as possible. The kinds of people sought were those involved in:
• local patient organisations - these could be disease specific, or more general (for example a health users forum or patients council)
• community health projects
• community care forums
• disability forums
• public involvement activities in relation to health.

These were recruited primarily through existing networks. Health council members were excluded, although several people who attended were, or had been, health council members. They were present because of other health-related activities.

It is worth noting that nearly all patient organisations have interests that are related to long-term, rather than acute, contact with the health service. The spread of patient interests represented in the discussion groups reflects this.

The cross-section of interests represented both locally and across all 15 groups was in most respects wide and varied. The groups were all dominated numerically by these health service user interests but in each case two people were invited who were working in the NHS and engaged actively in encouraging public or patient involvement. Typically these were public involvement workers or Local Health Care Co-operative (LHCC) managers.

Only one group was notably absent. Whilst a special effort had been made to include representation of ethnic minority interests, those invited had been unable to attend. The three who had been unable to get to the meetings were interviewed individually by telephone to redress this gap.
The target size of each group was 12 members. In the end, groups were held as scheduled in all 15 health board areas, and attended by 140 people in total (a mean of 9.3 per group). Organisations represented are listed in Appendix 1.

Representatives of voluntary organisations at a national level

Two meetings were held with representatives of voluntary organisations at a national level. The group size was smaller than that for the regional groups with 12 participants in total (a mean of 6 per group).

In addition a representative from the Scottish Community Care Forum made her views known by telephone.

In total thirteen people participated in the discussions or provided their views.

The organisations represented are also listed in Appendix 1.

WRITTEN SUBMISSIONS

All participants were reminded that additional written comments could be made. This was taken up by a few but mostly from those representing health councils.

Sources of additional written comments are provided in Appendix 2.

GROUP FACILITATION

Each group was conducted by one of three experienced group facilitators, all familiar with the background to the current policy issues. They took a neutral, facilitating role and encouraged the expression of
all relevant views without expressing any of their own. In each case the facilitator gave a short introduction to the topic outlining the main issues for consideration, in order to start the discussion off.

Written notes were taken by a scribe at each group. Each meeting was written up immediately afterwards by the facilitator, using the scribe’s notes, and the scribe checked this account. This report is based on those meeting reports and a verbal de-brief with the facilitators and main scribe. Since the time scale did not allow for taping, transcription and analysis of transcripts, verbatim quotations are not used in this report.

FIELDWORK PERIOD

Groups all took place between 18th January and 25th February 2002.
VIEWS ON THE CONSULTATION PROCESS

Whilst the majority were pleased to be consulted at this stage there were some comments about the process itself.

Those representing health councils, both chief officers and the chairs/members group were the most critical. There were concerns that existing staff of health councils and other health council members had been excluded from this stage of the consultation process. The offer was made for councils and officers to put further views in writing which, as noted above, many took up.

There were concerns that during this period of uncertainty for health council staff, they may start to leave denuding the movement of much talent and expertise. This group due to their experience and expertise should be closely involved with the next stage of consultation. Further, whatever the final configuration arrived at, there needs to be a comprehensive development programme for existing health council staff and members to assist with the transition to any new system.

One of the NHS chairs suggested that the consultation process should additionally include local authority based Social Inclusion Partnerships (SIPS) and patient involvement groups sponsored by LHCCs. This latter group were included in the regional groups but there has been no time or opportunity to include SIPS as yet.

Another view of a health council was that the effect of the pre-consultation would be affected by the generally poor understanding of the work of health councils around the country, and the fact that some of the organisations involved might be, in effect, competitors for the function of patient and public involvement.
It was suggested that in the later phase of consultation, information about the current roles, activities and achievements of health councils should be put out with the consultation document.

There were also comments from the regional groups about the compressed time scale for this part of the consultation process after little visible progress as a consequence of the publication of Our National Health.

There was also some cynicism expressed about the extent to which their views would influence. There was a widely held opinion that health and other public services were "consulting" people and organisations like theirs quite frequently already. This was welcome in principle but participants said that they were rarely told how their opinions had been used to shape decisions, if indeed they had, or even what decisions had been taken. They sought feedback about this pre-consultation exercise and an undertaking was given to provide a copy of this report.

**LEVEL OF KNOWLEDGE OF PARTICIPANTS**

As mentioned one of the concerns of health councils was that lack of knowledge of the activities of health council might impede the consultation process. It became clear in most, if not all, of the regional groups that knowledge of health councils and the way they operated was very patchy. Representatives of many patient-oriented voluntary organisations or community groups often knew very little about them, nor even about the health council in their own locality. A minority were more knowledgeable, including usually any NHS person present on the strength of their role in involvement, and sometimes representatives from any larger voluntary organisation. Representatives from national organisations were typically better informed.
This lack of knowledge had a very significant effect on the content and level of the discussions. Clearly, it restricted comment about the existing make-up and role of health councils, and although this was not the main focus of the discussions it formed the background to the policy proposals under consideration. It meant that many of the participants were coming fairly fresh to some of the issues, such as the possible functions of a re-shaped health council movement.

This effect varied from group to group and topic to topic, depending on the particular mix of people and knowledge. In some cases the lack of vested interest in the existing arrangements helped the free flow of discussion about what was needed. In others it held discussion back, or made it less constructive and focused than it might otherwise have been.

We draw attention here to the fact that this is an important finding in itself. All participants were recruited because of a known interest in a health-related issue and active engagement with a relevant local organisation, yet quite a large proportion knew little about their health council.
Assumptions underlying the ideas in Patient Focus and Public Involvement

Certain assumptions underlying the policy proposals in Patient Focus and Public Involvement were set out in the Briefing Paper. Facilitators were asked in the groups of regional and national voluntary organisations to concentrate on the proposals themselves, rather than on these assumptions, but to return to these assumptions at the end of the discussion if there was time. In most cases there was time, but discussion of the assumptions was relatively brief.

PRIMARY RESPONSIBILITY FOR INVOLVEMENT WITH NHS BOARDS

The first assumption set out in the Briefing Paper was that:

The primary responsibility for the process of involving patients and the public lies with the NHS boards.

In summary, the key points raised in connection with the proposal were as follows:

- There is agreement that the correct place for responsibility for public involvement to lie is with the NHS
- Public involvement must be adequately resourced
- Involving must mean not only listening but acting on what is heard
- Responsibility for public involvement must lie not only with boards and trusts but with LHCCs and practices
- The NHS needs to develop its own capacity for public involvement
- There should be a dedicated role for public involvement within the NHS
- The proposed new structure must have authority to exert influence on the actions of NHS
It was broadly accepted by all groups as the NHS was the right place for responsibility to lie. Both the NHS board chairs and chief executives argued that real involvement costs money and that the existing health councils were under resourced and so were restricted in what they could do. Any new structure for public involvement must therefore be adequately resourced.

The chairs/members of health councils group added that “involving” meant boards must not only listen but act on what they heard. This was a view that was echoed by many groups and an issue that this report will return to.

Those from the voluntary sector also had concerns that the NHS would pay only lip service to public involvement and go through the motions of consulting without taking action on the views expressed. A recurring and important theme was that whatever structure was in place it must have the authority and means to exert influence on the NHS.

One health council pointed out that the responsibility should extend not only to boards but to trusts, Local Health Care Co-operatives (LHCCs) and practices. The impression should not be created that it is seen as something lying with the higher authority at board level, when it should be an integral part of the mainstream work of all NHS bodies.

Many within the regional groups felt that they already had effective engagement and communication within the parts of the health service that were relevant to them and they would like to see this continue and develop. Chief officers agreed that existing public involvement activity within the NHS was patchy. However the NHS currently turn in some instances to the health council for assistance with public involvement activity and need assistance themselves to develop their own capacity for public involvement.
In some instances public involvement roles within the NHS are given to those with other responsibilities e.g. the Director of Nursing. It was thought that this could easily lead to a conflict of cultures and that a dedicated person should be assigned to public involvement work within the NHS.

Two within the NHS chief executives group argued that if the responsibility for public involvement lay within the NHS why were Health Councils needed at all.

WEAKNESSES OF LOCAL HEALTH COUNCILS

The second set of assumptions in the Briefing Paper contended that:

Local health councils as currently constituted

- Have their credibility undermined because they are not seen to be sufficiently independent of health boards, which select and appoint their members and staff
- Gain from being locally based but the whole movement loses from being fragmented.
- Have a range of functions which are carried out to varying extents by different councils.
In summary, the key points raised in connection with the suggested weaknesses of the current structure were as follows:

- There was strong agreement that credibility was undermined because they are not seen as sufficiently independent
- There is a poor awareness of health councils amongst the public
- Members of health councils were not considered to represent the public interest
- There have been rare examples of interference by health boards.
- Practical assistance was provided to some existing health councils in terms of Human Resources and IT support.
- There were concerns that the problem of lack of independence could be re-created in the new national body
- There was strong agreement that health councils gain from being locally based.
- There was less agreement as to whether the movement loses from being fragmented.
- There were advantages seen in having a national organisation as long as local flexibility and autonomy were retained.
- There was agreement that there are a range of functions which are carried out to varying extents.
- Variation between health councils was not necessarily seen as a weakness.
- There was agreement that health councils were due, or overdue, for reform.

Assumption 1: Health councils have their credibility undermined because they are not seen to be sufficiently independent of health boards, which select and appoint their members and staff.

The first of these assumptions was very widely agreed with by all groups.

The main issue raised was in connection with the perception of independence since the majority of the public or indeed voluntary
organisations don't know enough about the activities of the health councils to be aware of their lack of independence. A number of chief executives therefore questioned the “credibility with whom” since the majority will be unaware if the current relationships between health board and health council.

The other key issue concerned the appointment of members. Some of the regional groups argued that the method of appointment - in most areas via response to open advertisements - meant that members had no natural networks or constituencies. Chief executives of the NHS also questioned claims of members to legitimately represent the public interest and questioned whether their role might become confused with those members of the health board who too are there to ensure that the whole public was served.

Health councils argued that their current means of appointment were fair and ensured no domination by professional or vested interests.

A small number within the regional groups argued that in practice health councils were able to operate quite independently but that there was a lack of formal independence which was a handicap. Health councils too agreed that in practice there was no interference from boards. However a few mentioned examples of interference and it was thought that formal independence would ensure that this would be no longer possible.

Chief officers whilst not experiencing any interference did mention that that the practical assistance that came from boards in connection with pay, personnel services, computer and other office support was very valuable. Nevertheless there was agreement that that the existing appointment processes for health councils should be redesigned to strengthen their independence from NHS boards.
Health councils also raised a warning note about the possibility of recreating the problem of perceived lack of independence at national level with the new proposed body. There had been instances in the past of attempts to control views voiced by the SAHC.

**Assumption 2: Health councils gain from being locally based but the whole movement loses from being fragmented.**

The second assumption was usually split into its constituent parts. There was widespread agreement amongst all groups that the local base was important, indeed essential. This was a great strength. There was a strong desire expressed to retain and strengthen this local base. It was also emphasised by the chairs/members group that being member-based was also a big advantage.

Feelings about the second half of the assumption - that the movement loses from being fragmented - were not so clear or general. In about half the regional groups there was broad agreement with this assertion, but many confessed that their knowledge of the wider health council movement was too sparse for them to be able to offer an opinion. One of the chief executive's group remarked that their capacities were severely limited by their size and lack of resources.

There was some apprehension that the move towards a national structure might prejudice the local roots of health councils, and introduce rigidity and bureaucracy; in several groups it was argued that local flexibility should be retained.

Views were slightly different amongst the chairs/members of the health councils group. There was also agreement that the potential from joining forces was not fully realised, and a consensus that a national body would be a positive step. They varied, however, in the extent to which
they felt this should be a “top-down” body. Some seemed to want it to be a fairly strong body, controlling the direction of local activities; but a greater number emphasised the importance of local flexibility, and wanted a measure of local autonomy.

There was a feeling that the Association itself had, in the past, done some useful work in the field of training and dissemination of good practice, but that this had been less true in recent years.

Among the chief officers’ group, there was some support for this assumption, implied by support for the professionalising of the service that participants thought a national organisation would make possible. However, others questioned whether so-called “fragmentation” was a disadvantage at all: local areas were all very different from each other and needed different approaches. National policies and hierarchies would be an unwelcome dead hand in places like the islands.

**Assumption 3: Health councils have a range of functions which are carried out to varying extents by different councils.**

Health councils chairs/members and chief officers and NHS chief executives and chairs largely agreed with this assumption. However those within the regional groups had little confidence in expressing any view on the third assumption, again mainly because participants felt they did not know enough about what health councils elsewhere did. Those views that were expressed were mixed.

Not all agreed that variations were a weakness. Some agreed that consistency would be better, and would enable the role of health councils to be better and more widely understood by the public; others felt that the ability to interpret the role flexibly was a strength, since the contexts in which they were operating were so different.
One chief executive definitely agreed that clarity about function was important and that the national structure should help in this regard.

The chairs/members group indicated that variation reflected the different priorities and circumstances of different areas. Some thought that it would be useful to have more direction and uniformity: some functions at least should be “core”, so that the public could have a clearer sense of what they were about.

Clarification and simplification of the functions of health councils would be widely welcomed by most in the chief officers' group. However, they too felt that it was to be expected that different Councils should take differing views of their roles since the areas in which they were working were very different.

**Other views on the existing structure**

In addition to the above assumptions the health board chairs expressed the view that health councils were generally bureaucratic and not very effective. There were some exceptions: one Chair, for instance, said that the Council in his board's area had a high profile and put forward strong and independent views, though it had to be said that this tended to be on certain kinds of issue and the Council's connections with its various constituencies were not evident.

Overall however, there was agreement that health councils were due, or overdue, for reform.
THE NEED FOR CHANGE AND OVERALL OBJECTIVE

The Briefing Paper put forward the view of Patient Focus and Public Involvement that:

- A revised health council structure is needed.
- The main objective of the new structure would be to build the capacity of patients and the public to be involved in a meaningful way in the development of the NHS.

In summary, the key issues raised in connection with the need for change and the main objective of the new structure were:

- The need for additional functions in relation to:
  - The ability to pick up health issues that were not the preserve of special interest groups
  - The ability to take up issues raised by individuals
  - A watchdog function in relation to the delivery of healthcare as well as performance in public and patient involvement
  - Have “teeth” and the power to effect change

- There were concerns about:
  - The implied loss of the role to monitor performance in the delivery of healthcare
  - Added bureaucracy any new structure might bring
  - The views of service users not always being the same as those of the public and the tensions this could bring.

- The structure should:
  - Not duplicate existing structures but link to or be part of them
  - Be visible and understandable to the public
There was general agreement amongst most groups that some change was desirable. However the agreement on the level of change that might be envisaged varied quite markedly as did their views of objectives and the functions that the new health council structure should be responsible for.

The majority in all groups had little argument that the health councils should build the capacity of patients and the public to be involved in a meaningful way in the development of the NHS. However the chairs/members did not see it as the prime role and saw other functions that should also be key within the health councils remit. They were:

- the ability to pick up on health service issues that were not the preserve of some special interest group and bring them to public attention (the right to attend board meetings, and to be consulted on service changes, were vital tools for this purpose; to be the lay voice, the voice that asked the daft questions, etc., and challenge the professional consensus)

- the ability to take up issues or difficulties brought to them by individual members of the public who might never want to join a special interest group and support those people in trying to resolve them

and finally, the overall “watchdog” function:

- the ability to monitor and assess not just the NHS board’s performance in public and patient involvement, but its performance in delivering health care.

Indeed some wanted this role expanded to cover nursing homes and community care facilities and to have the power to visit them.
Chief officers were also concerned at the implied loss of a role to act as a monitor/assessor of the NHS’s performance in delivering good healthcare. Whilst some would argue about the legitimacy of the health councils having this role, it was their view that taking this role away completely would mean that there was no body left with the authority to take up concerns that were not those of some specific patient or community group. They believed that many such groups, even if they took up service user or community concerns, would not have the expertise to investigate and follow them through, or carry sufficient weight with the NHS. “Empowering” patient and community groups sounded good, and was good where it worked, but would be very patchy. Health councils had the experience and the knowledge to be able to take up issues and get effective action.

NHS board chairs were less likely to pick up on the need for any added functions. Their concern was rather with the need to ensure that whatever new structure was put in place should not be bureaucratic and cumbersome as some clearly saw the existing structure. Their view was that the existing structure was failing to do an effective job of involving patients and the public and some felt that they were not close enough to the real concerns of patients or the public, instead focusing on special issues like closures.

The regional groups were at a disadvantage in discussions due to their lack of knowledge of the existing structures but some general themes emerged as to the role that a revised health council structure should adopt.

- the structure should have “teeth”, the power to effect real change; it was no good patients or the public being consulted and then having their views forgotten about or ignored
• the new structure should not duplicate those already in existence, or create confusing overlap; rather it should build on what is there already

• the new structure should link in with, or be part of, those concerned with public involvement in community care, in other social services, and in community planning; the Joint Futures agenda was mentioned often

• the structure should allow for individuals to have their views heard and supported, not just those of organised groups; this should include supporting people when they wanted to make complaints, and it should link in with, support, or promote advocacy schemes.

The above four themes were strongly present in most discussion groups.

Another theme raised in several groups was:

• the need for the new structure to be visible to and understandable by the general public, much more widely than the present Health Councils were.

Few in the regional groups argued against change although there were a few dissenters and one group saw no need for a revised structure at all.

There were some concerns expressed by the NHS Chairs group.

• The risk of minority interests taking over the involvement machinery and whipping up opposition, particularly to major service of use. What checks and balances were there in the system to prevent this?

• There were concerns that service users views were not always the same as the views of the public and that tensions could arise. The
NHS was thought by this group to have developed satisfactory methods of involving those who experienced disadvantage whilst involving the wider public on issues relating to acute care were less satisfactory.

- That there existed other valuable mechanisms to assist people to engage with the NHS and there should not be reliance on Health Councils to solely undertake this role.

However another view was that if the NHS could demonstrate that they had followed good practice in getting the public’s views, their decisions would be more defensible even if there were vociferous minority interest and a revised structure of health councils could assist in this process.

FUNCTIONS OF HEALTH COUNCILS IN FUTURE

The Briefing Paper repeated the view propounded in Patient Focus and Public Involvement that the three main functions of health councils in future should be:

- Development: finding good ways for the public, patients and the community to get involved effectively
- Providing feedback: supporting people in making their views known
- Assessment: Holding the local NHS responsible for how well it is involving people

The three main functions outlined above were broadly approved of by all groups. There were suggestions from most groups as to additional functions that might be added to this list or broader interpretations of the above three functions. These suggestions came primarily from the health council chairs/members group, chief officers groups and the
regional and to a lesser extent the national groups. The NHS chief executives' group was the least likely to suggest further functions.

In summary, the main suggestions in relation to the appropriate functions of the Scottish Health Council were that they should include:

- proactively raising issues of concern
- monitoring the delivery of healthcare services
- supporting those who wanted to make a complaint
- lobbying for change
- maintaining their existing power to visit premises
- adopting a watchdog function (others called this monitoring or policing)

If the function to proactively raise issues of concern were to disappear, some chief officers felt that the health council's existing knowledge of issues and how to tackle them might be lost with a plethora of interest groups pursuing their separate agendas rather ineffectively. By contrast, some others approved of the implied shift arguing that traditional visits to hospitals etc. had little effect. They approved of the "empowering" objective, and thought that a professional service giving training and support would have a real effect. The balance of opinion seemed to be in favour of the shift.

Chairs/members and chief officers wanted it to be made explicit that the function of supporting people who wanted to make a complaint about the Health Service was retained. Most regional and national groups assumed that this would be covered under the heading of "Providing Feedback: supporting people in making views known". Health councils saw this as important for a number of reasons, not least that it gave one route for the Council to keep in touch with the issues that were concerning service users.
Chief executives view of the health council's role in relation to supporting complaints was less clear. There was a consensus that a system for supporting complainants was necessary and desirable. For some, this was explicitly because such a service helped defuse many complaints and "damp down" the "less rational" ones, but more generally there seemed to be a feeling that it helped complaints to be used more constructively. The function of experienced health council staff in this respect was appreciated by some; it helped to have advisors who were familiar with and understood the NHS system. There was also an acknowledgement of a need for further staff training in handling complaints.

However, there was clear disagreement over whether this should be a function of the new health council structure. Some thought it should be, others thought not. There were two or three who thought that the possibility should be explored of subsuming support for NHS complainants within a more generic service, perhaps based on or modelled on Citizens' Advice Bureaux. One participant drew attention to the work of the Royal Society of Edinburgh on mediation, and asked how this might affect the future of complainant support services.

Two views on advocacy were expressed. One voice supported it and thought more should be done. Another tended to see it negatively, because of a perceived tendency for advocates to support and intensify grievance rather than seek constructive resolution.

Regional groups were concerned that the proposed structure lacked power or teeth to make a difference. This was a strongly held view although often implied rather than clearly articulated. Some echoed the view of health council chairs/members that the power to visit should not be lost. They were concerned that the new structure should not be restricted to reacting to issues raised by others, whether in the NHS or in patient or community groups, but have the power to monitor services.
in its own right and pro-actively raise issues of concern.

One Council expressed the view that if the Council were engaged both with supporting public involvement (through the development/feedback functions) and assessing it, there could be a conflict of interest.

**DEVELOPMENT**

There was a common view that a development role was a key function for the Scottish Health Council.

The following key issues were raised in connection with the development function:

- The need to develop capacity for public involvement within the NHS
- The role of the development function within the context of existing work being undertaken by local authorities (especially community planning) so as not to duplicate the work of others but to link to it
- The scale of the task must be recognised and resourced.

Both regional and national groups indicated that there was a need to develop the capacity within the NHS to undertake public involvement. Regional groups described the current culture within the NHS as being unreceptive and unresponsive to involvement and that this needed to change.

Chief officers agreed that the capacity of the services themselves to listen to and respond to these views and ideas should be developed as part of this function. Chief executives hoped it would advise on good practice in patient involvement and assist in development of guidelines for boards and trusts. However, they also asked how far this kind of development
would also be a task for NHS boards themselves, if the prime responsibility for involvement was to become theirs.

Some within the national groups indicated that if the health councils were to play a role in assisting within the development within the NHS this might result in a conflict of roles. Whilst there was a view that the NHS must change the way it engages with patients, the development within the NHS was seen not to be a role for the health council but for NHS management.

NHS chairs agreed that there was a need for a culture change within the NHS as a consultation, even if superbly done, was useless if the results were not accepted and implemented by staff. There was already some good work (for example in LHCCs) but this was far from universal.

National groups were concerned at how the new structure of health councils and their developmental role fitted in with other existing organisations and agencies whose role was similar to that proposed for the SHC.

Chief officers also raised the issue of other organisations and indicated that involvement should not be viewed within the context of health services in isolation, instead a broader, more strategic overview of involvement in local areas should be developed, with links (for example) to community planning. The Scottish Health Council should therefore take a strategic overview of public involvement in its area, linking to the efforts of other bodies. Networks across Scotland should be encouraged for discussion, debate, learning etc.
Chief officers emphasised the importance of setting a direction nationally so that all organisations involved in developing mechanisms for involving local people in the NHS in Scotland can agree common definitions. Some common understanding of what public involvement is in the context of the Health Service, and what kind of activities it comprises, are prerequisites for the development of best practice.

NHS chairs indicated that the NHS could learn from local government who have been actively pursuing ways of involving the public, and though they are far from perfect, they are often ahead of health.

There were also comments relating to the scale of the task which was seen by one in the national groups as being so enormous as to be almost impossible. One or two of the chairs’ members groups also alluded to the scale of the development role and suggested that this might be a responsibility of the NHS board. If it were to be a role for the health council, the scale of the task must be recognised and the requisite resources provided.

In addition there were comments relating to the staffing and skills issues that this new structure presents. The chief officers indicated that there would be a need for dedicated staff with core competencies in patient and public involvement. Training would be required and staff coverage ensured in remote and rural areas. This raised the further issue of funding.
FEEDBACK

The following key issues were raised in connection with the feedback function.

- The role of the Scottish Health Council in relation to complaints
- The role of the Scottish Health Council in representing patients’ views
- The extent of its role in connection with gathering information and forming and putting forward a view of the basis of that
- Its relationship with advocacy services
- How the Scottish Health Council can support individuals as well as organisations
- The impact of the feedback from patients and the public in bringing about change or improvements in services

There was agreement that this should be a core function and that help was required to help patients and community groups to communicate with the NHS and NHS professionals.

The national group felt that complaints should be dealt with in the first instance by the provider of the services. There were concerns that if the Scottish Health Council were to get involved in complaints to any extent other than supporting them through the system they would be in danger of getting bogged down and reverting back to be a reactive organisation.

NHS board chairs and chief executives welcomed the shift to supporting patients and the public to get their views across, rather than speaking on their behalf.

The need for the new arrangements to provide an accessible and effective route for individuals to get their views across was a heavily
emphasised and consistent message of those in the regional group. It was not clear to them from the Briefing Paper where this function lay and many people were concerned about this. People often did need a lot of support, whether because they found the NHS structures and methods unfamiliar and intimidating, or because they were afraid of repercussions in the service they received for themselves or the people they cared for.

The national groups took the view that the SHC should not only assist and guide the public and patients in making their views known but should have a role in gathering information, and forming and putting forward a view on the basis of that, i.e. it should have some kind of lobbying role.

Their role would be to distill views of others and use this intelligence to inform policy. They were unclear as to whether this was an intended role for the SHC. Not all adopted this view and others felt that the role of SHC should be confined to developing, encouraging and assisting public involvement with the NHS.

Participants in several of the regional groups wondered how the new structure would tie in with advocacy functions; no clear view emerged.

There were concerns expressed at a number of different groups concerning whether the support provided by the Scottish Health Council would extend to individuals as well as organised groups. Some chief officers felt that the proposed structure may exclude many of those (“non-clubbable” people, or non-joiners of organisations) who might otherwise have recourse to the health council.
Regional groups also raised this issue. Existing health councils were widely seen as performing an important function in supporting individuals in making their views known, especially in supporting people who had a complaint to make. This function must not be lost.

The national group indicated that the NHS should have an obligation to report back with recommendations to let them know what was happening as a result of the feedback that was provided. The chairs/members groups argued that systems needed to be in place to ensure that the end result and the views expressed by the public were harnessed to change or improve services.

**ASSESSMENT**

Again this function was broadly accepted by all groups as being an important function. The interpretation of the role varied.

The following key issues were raised in connection with the assessment function:

- The impact of the public involvement process must also be assessed
- Whether the assessment role should be expanded to include monitoring of service delivery
- Demarcation and relationship to other bodies which also have an assessment role e.g. CSBS and SHAS
- The possibility of conflict of interest

The first of these issues, the impact of the public involvement process was the issue that was most frequently raised and about which there was significant concern.

The national groups saw the proposed assessment function as being
focused only on the public involvement process and not on the delivery of the outcomes of the public involvement process. It was seen as important that the NHS had not only listened to patients but that they had acted on what they heard. They felt a lack of assurance that the NHS would indeed respond to the concerns of patients and the public.

The regional groups too wanted to ensure that the new health council structure should have powers to ensure that NHS boards not only complied with the requirement to involve patients and the public, but to listen to the views expressed and alter services in response.

The chairs/members group also wanted to see the assessment role expanded to cover not only the extent to which the NHS had carried out “involvement” activities, but the extent to which this had affected and changed the services. This point was particularly strongly and insistently put. Chief officers also agreed that without holding the NHS to account for whether public involvement had any impact, the assessment function would be a bit of a dead duck.

Only the NHS board chairs welcomed the assessment role being focused on public and patient involvement and not on the much wider arena of delivery of health services.

The chairs/members group took the view that the impact could not be measured without recourse to assessing services. Some within the national groups took the view that the assessment role should be expanded to be able to monitor services and should not be confined to assessing the public involvement process.

Some chief officers felt that if the assessment function were too narrowly defined the existing power to hold NHS boards/trusts accountable for service provision might be lost. Some thought that this power could be
taken on by patient groups and community organisations. If properly supported they could discharge this role even better than the current arrangements.

A few of the regional groups mentioned two other bodies who have a remit for quality of service, the Clinical Standards Board for Scotland (CSBS) and the Scottish Health Advisory Service (SHAS). Participants speculated in general terms about possible issues of demarcation of roles between these bodies and the health council structure.

Chief executives also questioned how the functions of this whole structure would tie in with the activities of the Clinical Standards Board, who already carry out assessments of “generic standards” that include substantial elements of assessing information for and responsiveness to patients. There could be duplication and/or confusion. A similar point was made by an NHS board chair.

The national group took the view that the assessment role needs to be tied into the Performance Assessment Framework (PAF) and its role should be wider than commenting on the public involvement process but to commenting on the impact of the public involvement process on services. The chairs/members group envisaged a health council presence and voice at the NHS board’s annual accountability review meeting, when the chief executive of the NHS in Scotland was also present, and welcomed the prominence this would give their views. Being at the annual Performance Assessment meeting when public involvement was discussed was thought to be a potentially powerful and useful function.

Finally there was a view by a NHS board chair that the assessment function was in tension with the others, because there was a suggestion that it might be assessing the effectiveness of its own work.
The new health council structure

Following Patient Focus and Public Involvement, the Briefing Paper suggested that the new health council structure should be built around three elements:

- a national body called the Scottish Health Council
- local offices of the Scottish Health Council
- local Health Service User Forums in each NHS board area.

The rationale for these proposals was that a national structure plus a local grassroots network would create the best combination to support people in making their voices heard.

VIEWS ON THE PROPOSED STRUCTURE

In general the greatest amount of discussion centred around the proposed Health Service User Forums. Some groups, most notably the health councils chairs/members and chief officers were entirely opposed to the idea of Health Service User Forums. Whilst there was generally a recognition that there was a need for a grassroots network there was no clear vision emerging as to how this might operate in practice.

The majority of the chairs/members group agreed with the proposal for a national body with local offices, with a minority demurring. The chief officers were more strongly in favour with a few reservations. There was also little enthusiasm within the regional groups, although lack of familiarity with existing structures hindered their ability to get to grips with some of the proposals and their implications. Regional groups interest lay in the local level with a strong desire to have a structure which emphasised local autonomy and power. They often mixed up the proposals for the local offices and the health service user forums sometimes not seeing the distinction between them. They provided little
comment on the national body, which was of greater interest to those representing voluntary organisations at a national level.

The main concern for NHS board chairs was that the proposed structure might introduce a layer of bureaucracy which got between the NHS and patients.

Views on the national body and its local offices

Many of these issues are linked and are discussed below.

Control

The national groups saw that tensions might arise between having a national body and local offices, which were responding to local needs. They saw the priority as having an organisation which was accountable to the people locally who use NHS services. Regional groups agreed with this. They gave a national body cautious approval, qualified by the proviso that it should be controlled by, rather than control, the local structures. A relatively small minority saw no need for a national body.

A few from the chairs' members group also expressed concerns about the need for control to come from local organisations rather than the other way around. This feeling was the strongest in the Islands councils.
A centralised body was likely to know little of the concerns of remote and rural areas and probably care little too. There was a danger that a national body, whether appointing staff or setting priorities might be insensitive to local issues and ways of doing things.

There were also fears that a national body was being proposed because it would be easier for the Scottish Executive to control.

NHS board chairs had no problem with the proposal for a national body. They had more doubts about the local offices and whether they could turn out to be Local Health Councils in another guise. They did however recognise that a local presence was needed but neither board chairs or chief executives touched on the issue of where control should lie.

In summary the prevailing view was that control should lie at a grassroots level. However the optimum structure which would allow this to happen remained unclear.

**Consistent approach**

The national group saw a need to have consistency between health councils and a national body was seen as one way of achieving this. However in addition to wishing a consistent standard of service they also wished to see flexibility in the local arrangements to meet local needs. There may well be some tension between these two desires.

Chief officers made little comment about having a consistent approach other than to indicate that they welcomed the national body as an opportunity to create a more professional service rather than a member led service. However there were also clear reservations about a national body within the group.
Chief executives made little direct comment about the national body other than to give support for the idea that it should introduce some coherence. As already mentioned, if boards were to be assessed on their performance in involving the public, there ought to be clear guidelines on good practice; and a national body should help achieve consistency in assessment.

**Number and spread of local offices**

The issue of how “local” the offices should be was received some attention from the regional groups. In the larger and more rural areas, the point was often made that one central office in the health board area was not sufficiently local or accessible. In most cases, however, groups came to the conclusion that only one permanent office was sustainable, from a resource point of view, and they came up with various suggestions about how to extend its outreach: rotating “surgeries” at various locations, a mobile office and proactive use of the internet were all suggested. The suggested definitions of sub-areas varied too: in some groups it was suggested that they should correspond to LHCCs, in others it was existing or former local authority areas, in others the areas covered by other bodies such as Community Care Forums.

**Other issues**

The national groups felt that a national body would be of particular importance for those representing low incidence conditions where they cannot achieve a critical mass of opinion to influence at a local level. These forums could communicate directly with the national body of the SHC. The national body was seen by this group as being at the hub of a wheel or a spiders web facilitating communication in many directions.

A national body would also assist in engaging with the two Special health boards which currently have difficulties in engaging with health councils.
VIEWS ON HEALTH SERVICE USER FORUMS

There were some who showed little enthusiasm for the idea of Health Service User Forums whilst others directly opposed the proposal. In the health council chairs/members group there was fairly uniform opposition and whilst there was more debate amongst chief officers, the consensus was firmly against them. NHS board chairs also expressed doubts about the Health Service User Forums.

Participants in the regional and national groups welcomed the principle of local influence and providing a mechanism for organised groups and individuals to feed into the structures but were not all were convinced, by any means, either that the user forums were necessary or that the proposed arrangements would work. All groups engaged with the idea and explored some of its possibilities and implications but the majority had no clear vision of how it would operate in practice. Whilst participants did not think there were no solutions to some of the problems that were raised, they would wish to have reassurance about them before being fully converted to the idea.

The key points raised in connection with Health Service User Forums were:

- How such a potentially large group of organisations could be accommodated
- Fears that the forum could be dominated by narrow or minority interests.
- Fears that it would be a forum of paid workers and not service users - involving individuals
- Lack of clarity of the role of the HSUF
- Volunteer fatigue could undermine the effectiveness of the Health Service User Forum
- A need for a relationship to existing structures - in particular Community Care Forums
- Flexibility to respond to local needs was to be encouraged
**How could such a large group of organisations be accommodated?**

The national group took the view that the number of people or organisations that might need to be involved would be so great that it would be very difficult to manage. There would need to be multiple forums to be able to accommodate all interests. If it were unable to involve all, then it would be accused of excluding certain groups. The regional groups too grappled with how the forum might work in practice. If it were to be open to a wide membership, which was the ideal, it would be too large or unwieldy for meetings to be constructive.

There was some discussion of the form that the forum would take and the view of the national group was that it would be a meeting but there was a suggestion that other means of communication could be used including having a virtual forum.

In addition to the suggestion of having a geographical spread of forums, there was also the possibility to have a forum representing the views of ethnic minorities or specific conditions or disabilities.

Regional groups envisaged networks of forums at a more local level than that of the entire health board area.

**Fears that the forum could be dominated by narrow or minority interests.**

The national and regional groups indicated that the health service users forum might attract those with minority interests or an axe to grind, and as such the forum could become a battleground of those with fixed but competing views. It was important that the forum allowed for discussion of a more general nature.
Existing health councils chairs/members and chief officers also mentioned the danger of the forums being dominated by a few groups or individuals pursuing narrow vested interests, rather than the wider interests of patients and the public as a whole. Health councils already worked with local voluntary organisations where appropriate - which was a great deal - but in their view it would be wrong to have them running the show.

Chief executives were also concerned about the possibility of overly strong influence from minority groups and would like to see checks and balances built into the structure to prevent such skewing.

**Fears that it would be a forum of paid workers and not service users - involving individuals**

Chairs/members of health councils and chief officers argued that if Health Service User Forums were to exist then membership should be open to individuals as well as to organisations. There was a fear that the forum would in practice be a forum of paid workers (voluntary service co-ordinators) and not health service users.

The regional groups too advocated a structure which would not restrict membership to organised groups. Individuals too must have the ability to take part and have their say. Indeed, a potential strength of a Forum was that it could offer opportunities not just for the usual stalwarts to put forward their views, or the paid co-ordinators of the larger voluntary organisations, but for individuals as members of the public or as service users.
Lack of clarity of the role of the HSUF

Many from both the chairs/members group and the chief officers felt that the role and functions of the proposed forums were unclear at best and there was scepticism that they could generate any clear identity, programme or momentum. They saw the forums, if they were to exist, as acting as a channel for access to the professional services provided by the Scottish Health Council in terms of training, support and development - they would be membership organisations. One annual meeting might suffice, plus the generation of an annual report concentrating on the extent and quality of public involvement. This view was quite contrary to and significantly narrower than the view of the regional or national groups.

Volunteer fatigue

It was the view of existing health councils that volunteer fatigue would mean that forum work would take second place to their primary interest.

NHS board chairs also expressed concerns about the ability to get people involved in yet another series of meetings and there was danger of consultation fatigue.

Some from regional and national groups also mentioned the difficulties in getting volunteers along to another set of meetings.

Relationship to existing structures - in particular Community Care Forums

The national group would also not like to see the SHC impose a structure for Health Service User Forums when there are already very
good existing structures. The most obvious of these are the existing structure of Community Care Forums of which there are 47 in existence across the country. These are all funded differently. It was felt that user forums would work better by working with existing structures. The local offices should have flexibility to build on what was already in place locally. One felt that the resourcing of the health service user forum was essential if it was to work well and effectively. She also felt that there should not be a separate forum for community care and another for health and these were inextricably linked and it made sense therefore to bring these together under one banner perhaps under a heading of “Scottish Health and Social Care Forum”. This would allow for the wealth of experience already built up within Community Care Forums to be used.

Those from existing health councils shared reservations about the advisability of creating such a structure alongside others that already existed: community care forums, community planning networks and so on. There was already too much confusion and perhaps not enough lay effort to go round. Would it not be better to build on existing arrangements? Generic forums would surely be a better idea, and have the potential to work across agency boundaries. There was some support in the chief officers’ group for the idea of “Community Involvement Networks” with a geographic base, but this did not carry the majority.

The relationship of the forum with existing structures was also a recurrent theme of the regional group discussions. Those voluntary organisations that already had a constructive relationship with relevant parts of the health service said they did not want to have to communicate via some extra layer of bureaucracy. There were Elderly Forums, Mental Health Forums, Community Planning Forums, Community Care Forums, panels of 100 or 200 local people, and so on. There was a danger of duplication and confusion, of extra meetings and
bureaucracy, and of overloading the limited pool of committed volunteers. Rather than create a new structure, it would be better to build on what is there already.

A closely related theme, which nearly all the groups brought up, was that people needed to relate not only to health services but to community care and other local authority services. If it could possibly be avoided, people should not have to grapple with separate structures for becoming involved with each service or agency.

There was a positive endorsement for Community Care Forums, which were seen to be doing a good job. Similarly the local authorities were perceived as being more advanced than health services in undertaking public involvement and the structure should pay attention to the ways that local authorities engage with the public and make sure it ties in with these. One suggestion might be a generic forum where the public could engage with both the local authority and the NHS.

In the chairs/members group the role of lay members of health councils on the existing model was stoutly defended. They gave a lot of time; they did a lot of the work of health councils (voluntarily); they were close to their publics; they had a broad interest in health service issues, not just in relation to a single disease or a small locality. Most came from advertising to the general public, and people put themselves forward. Given this, where was the rationale for forums?

**Flexibility to respond to local needs**

The national group indicated that it might be possible to have different structures in different areas. Flexibility was to be encouraged whilst at the same time ensuring consistency of service across Scotland. Chief officers echoed this view.
OTHER ISSUES RAISED IN RELATION TO THE STRUCTURE

Independence of the Scottish Health Council was also raised as an issue and this related directly to funding arrangements. National groups took the view that funding arrangements must not be variable across the country and should come from the Scottish Executive. In order to ensure independence it was suggested by one that funding should be directed via an independent trust fund.

Chief executives suggested that in order to make any new structure effective more money would be needed than was used to fund the present system.

There were concerns expressed by the chief officers that the proposed structure would have them subordinate to a Head Office, which would be an unwelcome change. Some believed that local officers would have a lower grading and salaries than chief officers currently had.

Chief officers also did not want to get caught up in the role of supporting or acting as administrator for a lay management committee. Most present felt that they had managed to get away from that kind of relationship with their Council and did not want to return to it. There was no discussion as to what their role in supporting any forum might be.
Participants were asked to discuss the issues that were left open in the paper Patient Focus and Public Involvement. Many of the issues discussed under these headings had also been raised by participants in the meetings under the other headings of the three functions or the proposed structure for health councils.

**TOPIC A: GIVEN THE FUNCTION OF THE SCOTTISH HEALTH COUNCIL, WHAT FORMAL POWERS SHOULD IT HAVE?**

The main suggestions were:

- Ability to take sanctions if no response from NHS
- The powers of a regulatory authority - Offhealth?
- Power to force people to meet, listen, answer questions, provide access to information
- To raise matters of concern - set the agenda and do so publicly
- Audit / monitor services (some wanted power to visit)
- Be provided with reports on public involvement activity and proposed action
- To be consulted on proposed service changes
- Attend and speak at board/trust meetings
- Clout or teeth to hold NHS to account

National groups took the view that the SHC should have the ability to take some sanction if there was no response from the NHS to the views of patients. They wanted the new body to be taken seriously. One view was that it should report directly to the Minister for Health. This would be an indication that public involvement was indeed taken seriously.

One national group saw the new SHC as having a regulatory authority in a similar way to the regulatory bodies within the private sector - a sort of “Offhealth”. These bodies were seen as having bite because they...
had significant powers. It was this “bite” or “teeth” that was seen as essential to the success of the new SHC.

They felt that the SHC should have the power to force people to meet with them, listen to them and to answer questions. They should also have access to information. This view was shared by those in regional groups.

The regional groups additionally thought that the SHC should have the power to raise matters of concern i.e. to set the public involvement agenda both locally and nationally. They wanted this power to raise issues to be in the public arena.

Two regional groups wanted SHC to have the power to audit or monitor services and one wanted to have the power to visit NHS services.

Other powers that were mentioned in only some of the groups were: to be consulted on proposed changes in services; to be provided with reports on public involvement activities together with the actions that were taken as a result. The SHC should also be able to publish their own reports on the results of actions taken by the board. In two groups there were suggestions that there should be a right of attendance and speaking at the NHS board and relevant committees.

Many of those within the regional groups could not articulate exactly what formal powers the new organisation should have but they were sure that it must have clout or teeth to be able to hold the NHS to account.

Health council chairs wanted the new body to have similar powers to the existing structure with corresponding rights at a national level. Like
the regional group they saw it as essential to have the right to attend and speak at board or trust meetings. They also wanted to continue with the right to visit and monitor NHS premises.

Some spoke of the potential value of being able to participate at LHCC level.

**TOPIC B: WHAT ROLE SHOULD THE SCOTTISH HEALTH COUNCIL HAVE IN RELATION TO THE PERFORMANCE ASSESSMENT FRAMEWORK FOR NHS BOARDS?**

The main findings were:

- Right of attendance at accountability reviews and comment on performance of public involvement activity
- Develop the tools to assess and evaluate public involvement for use in PAF
- To cover not only public involvement but the impact on services

The chairs/members group thought there should be a right of attendance at the accountability review meeting and to comment in the presence of representatives of the NHS Management board on the claims of the NHS board to have done a good job on patient and public involvement.

The chief officers' group went a stage further and suggested that measures and tools to assess and evaluate public involvement be developed for use in this performance assessment process. These measures should be based on community development frameworks such as “Achieving Better Community Development”, developed by the Scottish Community Development Foundation.
Relevant to both questions A and B was the generally expressed desire for the new arrangements to assess not only the existence of public involvement but the impact that this had had on services. However, there was little in the way of concrete suggestions about what powers or procedures, over and above existing powers, could make this a reality.

**TOPIC C: TO WHOM SHOULD THE SCOTTISH HEALTH COUNCIL BE ACCOUNTABLE?**

This was discussed by both national groups and by 7 of the regional groups.

Suggestions concerning who the SHC should be accountable to include:

- The Minister for Health
- The Scottish Executive - but with links to the Minister
- Health and Community Care Committee
- The public
- There was a strong need for the Scottish Health Council to be able to demonstrate clear independence.

One of the national groups felt that if the SHC was accountable to the Minister, then other politicians would have the right to comment. The other group proposed that it be accountable to the Scottish Executive but with links to the Minister. They both felt that access to the Minister was essential in ensuring change.

One of the regional groups also mentioned the Minister for Health.

One further suggestion by national groups was for the SHC to be accountable to the Health and Community Care Committee of the Scottish Parliament. This would allow a cross-party approach which was
seen as beneficial. The downside was that they believed that the health committee does not have the power to change things and this was an essential component of their vision.

It was also the strong preference of the chairs/members group that SHC be accountable to the Health and Community Care Committee of the Scottish Parliament. This had gained the respect of health councils, and it would ensure that the new body would not become subject to the control of the Scottish Executive or the Minister. The form of this line of accountability was debated and because there was no precedent that anyone knew of, no clear view emerged; but it was suggested that various possibilities could be explored, including some sort of split between day-to-day oversight by the Scottish Executive but longer term recourse to the Committee.

Although one regional group had said that the SHC should be able to report to the Health Committee of the Parliament, none of the regional groups suggested that it should be accountable to the Committee.

Whilst some saw accountability up the way to the Scottish Executive or the Minister for Health others argued that it also had to be accountable to the public. It must therefore be accountable in both directions.

The clearest message from the regional groups was that the SHC should be accountable to “its members”, to “the grassroots” - by which was meant, apparently, whatever equivalent to the Local Health Councils emerged in the reorganisation. A number of groups also said that it would, of necessity, have to be accountable to whatever body funded it, which was assumed to be the Scottish Executive. Some sort of parallel accountability was envisaged. A smaller number were definitely against any line of accountability to the Scottish Executive.
One participant was less interested in its accountability than its impact. If it did not have impact the senior NHS managers would be likely to ignore it.

The new SHC would need to build up credibility and it was thought that this would be assisted by ministerial access and public transparency. It was felt that organisations like SHAS have written some hard hitting reports which once in the public domain have had impact. It would be hoped that this organisation would too have impact.

The theme of independence was also very prominent amongst the regional group discussions on accountability: participants exercised their minds about what routes of accountability could guarantee this.

In the chief officers' group there was speculation on what form governance might take: whether it would be a Special health board, whether it would be subsumed under whatever body succeeded CRAG/CSBS/SIGN etc., and so on. There was clear concern expressed over the possibility of it coming too much under the influence of the Scottish Executive/NHS Management board, and of too cosy a relationship developing, but no remedy was proposed.

Participants suggested that options should be presented in the later official consultation paper.

Clearly no consensus was arrived at, but there was a strong need for the Scottish Health Council to be able to demonstrate clear independence and to have a strong position which would allow its views to be taken seriously and be capable of influencing change.
TOPIC D: WHO SHOULD BE THE MEMBERS OF THE GOVERNING BODY OF THE SCOTTISH HEALTH COUNCIL?
WHAT KIND OF BALANCE OF INTERESTS WOULD BE NEEDED, AND HOW SHOULD THEY BE APPOINTED?

The key points raised in discussions of governance were:

- Whether members should be appointed or elected
- Methods of recruitment should appeal to a broad range of people
- Include representatives of local SHCs
- Recruitment from marginalised groups
- Prevent bias towards those representing chronic conditions
- Geographical and demographic representation (one per health board area?)
- Via Public Appointments Commission

There was a reaction to the use of the word “appointed” and some felt that members of the governing body should be elected. However, if elections were to take place then there would need to be a process put in place to allow for these elections and none were suggested.

There were concerns about the way that current members of similar bodies are appointed and whether this had sufficient general appeal to access a wide range of individuals. They suspected adverts only appeared in the broadsheets and the timescales for application were generally too short.

It was important that the governing body was large enough to allow for a full mix of individuals. It was expected that the board should comprise of representatives of local SHCs and there should be a requirement to recruit from marginalised groups.
There were concerns that more members may come from those groups representing chronic conditions. There was also the danger of getting interest groups on the governing body and there needed to be a mechanism to ensure balance.

Most of the chairs/members group suggested that it should consist of representatives from the various health board areas, some suggesting one per area and others suggesting a smaller body with representation on a regional basis. None however were clear about who would be eligible to become such representatives; they appeared to assume implicitly that there would be a pool of health council members on the existing pattern, despite the fact that the proposals do not suggest this. One Council member suggested drawing on the non-executive members from local areas. Another suggested advertising generally, and one suggested that members should be appointed but did not say by whom.

The chief officers' group thought there should be a small non-executive board appointed via the Public Appointments Commission.

The clearest message here was that there should be members from the various localities in Scotland on the governing body.

One regional group also said there should be an appropriate mechanisms to ensure that there were both men and women, and that there should be representation from ethnic minorities, and that the interests of other groups such as those of different sexual orientation were duly represented. There were, however, no suggestions as to how this might be achieved.
There was no clear consensus of the method of appointment but the balance of opinion was in favour of attracting a broad range of people from throughout the country.

**TOPIC E: WHAT ROLE, IF ANY, SHOULD THE SCOTTISH HEALTH COUNCIL HAVE IN RELATION TO SUPPORTING INDIVIDUAL MEMBERS OF THE PUBLIC IN PURSUING COMPLAINTS?**

The main findings were:

- SHC should have a role in connection with complaints
- A more strategic role is envisaged by some
- A role to monitor complaints handling
- To support and signpost but not handle
- Role should not extend to long term advocacy
- There were many other existing organisations to assist with complaints - do not duplicate the work of others
- To support not investigate
- Needs to be adequately resourced
- Include complaints which cross boundaries with social care

The view of the national groups was that the SHC should have a more strategic role in the complaints process. This was echoed by three of the regional groups who said that one role that the SHC might have locally was to monitor complaints, both so that they could check that they were being dealt with timeously and so that they might become aware of areas of the NHS that were serving people poorly.

Whilst there was agreement that the SHC should have a role in relation to members of the public pursuing complaints there was some debate about the extent to that role.
The national groups indicated the SHC should be there to support complainants and signpost but not handle complaints. There were already existing organisations in place at a local level to assist with complaints e.g. advocacy groups, patient's councils, ombudsman and there was no need to replace these.

The chief officers also spoke of how the SHC could relate to other organisations on this issue. Discussion turned here to advocacy. Although supporting complainants should be a part of the SHC’s work, this could not easily be distinguished in some cases from crisis advocacy. It should not extend to long-term advocacy.

In the regional groups that discussed this issue, one of the main themes was the need to link with other services, particularly advocacy, and not to duplicate what such services did. It was important not to confuse advocacy with complaints. There might well be a case for the SHC locally not so much to act directly in support of complainants, but to ensure that there was such a service and to direct people to it.

In the chairs/members group there was a clear consensus that this should definitely be part of the job of the Scottish Health Council. It was important, though, to define clearly what was meant: it should support complainants, not take on the role of investigating complaints. It was noted that complaints sometimes cross health/community care boundaries.

In the chief officers' group, too, the majority were strongly in favour, on the grounds that:

- people would bring their concerns anyway and the SHC would lose all credibility if it said its job was limited to building capacity; there was no clear dividing line between supporting collective and
individual views;

- the experience day to day of dealing with people's complaints would ground the whole work of the SHC in the reality of people's experiences with the health services;

- there had to be some mechanism for supporting complainants, independent of health boards, and any alternative would be both more expensive and less effective (real knowledge and expertise in the health system was needed).

One chief officer disagreed. This person argued that complaints, especially those that took time were a very small minority of all dissatisfactions and could give a seriously distorted view of where the priorities lay; and that other mechanisms offered a better avenue. If it had to be part of the role, appropriate resources would have to be provided because it was a time-consuming job, a point that was more widely agreed.

A further option was that branches of the Scottish Health Council could facilitate the development of generic services - that is, services that were not specific to health services but covered local authority services also - to support complainants.

Nearly all the five regional groups who discussed this topic said that one of the functions of the SHC should be to support individuals who had issues to raise with the NHS about their care, including those who wished to complain about some aspect of that care.

In summary there was agreement that the SHC should have a role in supporting patients in pursuing complaints. Many felt that this role should be confined to supporting patients although the degree of
support was not clarified. There was also a need to work with existing organisations who support people in making complaints.

**TOPIC F: HOW MANY LOCAL OFFICES SHOULD THE SCOTTISH HEALTH COUNCIL HAVE?**

One of the national groups said there should be at least one local office per health board area. There may be problems with this in areas such as Highland or Argyll and Clyde.

The LHCC structure which has approximately 100,000 population was thought to be a useful structure upon which the health service user forums might be based. There are 81 across Scotland and this was seen as an appropriate number and might encourage more user involvement at that level.

The consensus of health council chairs' members was one per health board area.

All three regional groups who discussed this were in rural areas, and all came down - after some discussion - in favour of one office in the area plus some mechanism - mobile office, local surgeries, use of the internet, tapping into local networks - to enable some presence in various parts of their wide geographical areas.

Otherwise, all groups either explicitly or implicitly assumed that there would be one office in their area.
TOPIC G: FORMAL POWERS OF HEALTH SERVICE USER FORUMS

There was considerable interest at a general level in ensuring that the respective parts of the system (SHC and Local Health Service User Forums) did have formal powers, and thereby “teeth”, but no clarity about what these powers might be. Indeed, groups frequently alternated between talking about these two elements of the system and did not distinguish at all clearly between the roles or formal powers of each.

One group was an exception to this, and discussed the relationship between the two parts in some detail. They highlighted various issues, such as the potential tension between the two, and to what extent the Forum should directly manage the SHC locally. The emerging consensus seemed to be that it should be able to hold the local SHC to account, rather than manage it.

More generally, in the groups that discussed this issue, the main common theme was that the local Forums should be able to elect a member to sit on the national governing body of the SHC.

Some groups accepted that the local Forums would elect “non-executive” members to the local SHC (though the term “non-executive” was not understood or liked), but were unclear about how this might happen; others were unsure whether this would be practicable or helpful.

TOPIC H: MEMBERSHIP OF HEALTH SERVICE USER FORUMS

There was a clear consensus that it should be open to all those who wanted to join - one group adding that commitment of interest was a necessary criterion, another wanting to exclude service providers (here
here they were thinking of private providers). Groups also said that Forums should be open to individuals to participate if they wished. One made the point that it was important that, even where organisations were the members of the Forum, every effort should be made to ensure that individual people - members of the constituent organisations, who were the end-users of services - took part actively, rather than always the paid workers.

This and other groups also emphasised that this would not be possible unless the methods of working of the Forums - the place and timing of meetings, their style, the way information was presented, and so on - were carefully planned.

One group said that membership should be “broadly representative of the local population”; another warned that, since the interests of many local organisations were not identical, there could be conflict in these Forums.

**TOPIC I: ELECTION OF NON-EXECUTIVE MEMBERS**

The one group that discussed this was ambivalent about the need for such elections, but if they were to take place wanted mechanisms to make sure that the people elected were not the paid co-ordinators of local organisations but the end users of services for whom these organisations were working. They also said that these volunteer members ought to be compensated for their time and effort with some payment.

More generally, as noted above, groups were divided and unsure about the advisability and practicality of such elections.
TOPIC J: RELATIONSHIPS BETWEEN COUNCIL AND FORUMS

As in other areas of discussion, the most prominent theme was that the power should reside at local level. This was expressed in various ways: that local Forums should elect members to the national body; that the national office should be “lean”, and not consume resources that could be used locally; that the local bodies should be able to determine their own priorities, and not be dictated to from the national body; and that local Forums should be able to feed their concerns into the SHC structure via their local offices and thereby influence national agendas.

Relationships between the SHC and health service user forums locally were not discussed in much detail. One other group did pay this some attention, wanting the Forum to have the power, with the local SHC acting in a facilitative, supporting role.

TOPIC K: RELATIONSHIP WITH COMMUNITY CARE FORUMS

All five of the regional groups that discussed this issue were concerned that there should be no duplication of effort. Two of them thought that cross-membership between the two bodies should achieve this, and two said that the two roles should combine in one body, perhaps called a Health and Community Care Forum. The fifth, from a dispersed rural area, said more generally that the existing network of Community Care Forums, which reflected the geography of the area, offered a “way forward”, without being more specific.

One representative of the community care network also advocated that the proposed Health Service User Forum work with the existing Community Care Forum network rather than setting up a new structure.
Main findings

- A perception that the proposed structure would be more expensive
- A potential loss of close and constructive relationships with boards
- A need to ensure adequate and equitable funding
- Experience and expertise of existing health council members and staff should not be lost
- A need to put transitional arrangements in place
- What would be the role of the Scottish Health Council in acting as a public voice to the press
- Must retain room for local variation
- The new organisation must have public visibility and clarity
- Scottish Health Council must provide feedback to individuals and organisations on whose behalf it was acting
- Expect the national body to be able to raise matters of concern in relation to the NHS at a national level
- To recognise the barriers to involving ethnic minorities and take steps to address these
- To recognise and acknowledge the role of volunteers
- If the new health councils were elected, there may be a potential tension between them and the elected members of local authorities

MONEY AND RESOURCES FOR THE WHOLE SYSTEM

Both the chairs’ members group and the chief officers’ group felt it was hard to see how the new system could be funded, within the current overall budget for health councils. They believed it looked more expensive than current arrangements. The chief officers argued that the type of work being suggested in local areas - of a community development kind - was more labour-intensive than their current style of work and therefore more expensive in itself - and there was the national body to be funded as well.
In addition NHS boards currently meet health council accommodation, human resources, information and communications technology, supplies and some other costs, and these services were extremely valuable. It would be vitally important in developing the new arrangements, therefore, that these 'hidden' costs were included in any costing exercise. Some Councils also argued that another potential loss might be the close and constructive relationships built up with boards over the years.

One Island Council pressed the point that in any new allocation of resources under a revised system, the special costs associated with work in the islands and other remote and scattered areas be borne in mind.

One of the national groups raised the issue of the resourcing of the SHC and the Health Service User Forums which was seen as crucial. Adequate and equitable funding across the country was needed to prevent the situation that exists at present where health councils and Community Care Forums are funded to different levels in different parts of the country.

How the funding was provided was also an issue. If the money is provided in a top down fashion then there is a danger of creating another quango. Local funding by contrast leads to a fragmented service as described above.

**CURRENT SKILLS, EXPERIENCE AND MOTIVATION**

Chairs and members wanted to emphasise the value of the pool of experience and motivation that they had built up over the years, and the waste that would ensue from simply discarding health council members. Members (as distinct from and in addition to staff) did a great deal of the work of Councils and brought invaluable perspectives as lay
people from all kinds of backgrounds.

The chief officers were likewise very much at pains to draw attention to the body of expertise represented by health council staff. The future of these staff in the new system was a matter demanding urgent attention, because some were already beginning to look for alternative employment on account of increasing uncertainty.

It was possible - indeed very much to be hoped - that many staff would be retained in the new system, but uncertainty about this was heightened because of the very different roles and skills that it might require. For example, the task of facilitating patient and public involvement demanded much more emphasis on skills of a community development kind. As a consequence, instituting a programme for training and development to help both staff and members prepare for and shape the emerging system was a vital priority.

A point of particular importance was that this pool of expertise and experience could not be re-created. Boards and trusts relied on it to a large extent already to help them engage with patients and the public in many ways that might not be widely publicised, and hence undervalued in the current exercise. NHS bodies left to discharge these functions using their own staff resources might find themselves very much at sea without this pool to call on for advice and help, so that the whole agenda might be set back rather than taken forward.

**TRANSITIONAL ARRANGEMENTS**

A suggestion was made by chief executives that the new structure could be considered, for the time being, a temporary or provisional arrangement, allowing for evolution and learning, before being set in statutory concrete. A similar point was made by one of the NHS board
chairs: this person suggested that the role of the Scottish Health Council should not be too closely prescribed to start with. Rather it should be set up with its broad functions specified, and allowed to work out its mechanisms and structures.

PUBLIC PROFILE OF THE NATIONAL BODY

It was pointed out by chairs' members that the national body would be expected by local interests such as the Forums, if established, and by the press and others, to give comments on health service matters and controversies currently in the public eye. The question was raised of how it might respond, and what role it was expected to have in speaking on such issues.

LOCAL VARIATION

It was argued on frequent occasions that, whatever the final decisions, there should be room for local variation because local needs and circumstances were so different.

PEOPLE WITH DISABILITIES

In a number of regional groups it was stressed that, whatever system was created, it should allow for access and active participation by people with disabilities, including those with communication difficulties.

PUBLIC VISIBILITY AND CLARITY

A recurrent theme was the need for the system to be better known than the current one and sufficiently clear and simple for everyone to be able to understand what the roles of its constituent parts were. People should be able to understand easily what body it was appropriate for them to use or speak to.
This was not necessarily an easy matter. It entailed constant awareness of the use of language, and avoidance of jargon terms and acronyms. It also entailed active “marketing”, in the sense of proactive efforts to make people aware of the existence of the SHC and what it did.

This was an important consideration that affected many of the policy issues discussed - for example, the name of the organisation.

**TWO-WAY COMMUNICATION**

Frequently mentioned by regional groups, in a number of different contexts, was the importance of two-way communication. Many people remarked that the NHS was now actively asking for opinions in many different ways, but that it rarely fed back the results of these consultations or what action had (or had not) been taken as a result. This led to disillusion with the process: it was hard to tell whether the effort put into formulating and communicating views - often considerable - had achieved anything at all. Without active and detailed feedback, it was possible that willingness to co-operate would fall away.

A similar message needed to be taken on board by the new SHC; it too would need to put a considerable amount of its effort into keeping people informed of what it was doing and what impact it was making. It was particularly important that it should communicate effectively with the people and organisations on whose behalf it was acting, for instance, the local Health Service User Forum and its constituent organisations, and other individuals with which it was in contact such as complainants.
POTENTIAL NATIONAL ROLE OF THE SCOTTISH HEALTH COUNCIL

One or two groups explicitly, and some implicitly, expected the national body to be able to raise matters of concern in relation to the NHS at a national level, either with the Minister or with the Health and Community Care Committee of Parliament, and to do so publicly. This would extend the role of the SHC beyond what is directly envisaged in Patient Focus and Public Involvement, where it is seen primarily as a facilitating body to enable others to raise matters of concern, mostly at a local level.

VIEWS OF ETHNIC MINORITY PARTICIPANTS

The views of the participants from ethnic minority organisations were generally very much in line with the majority views from the groups. Aspects receiving particular emphasis were:

- the need for involvement to be genuine, not token, and the need for the SHC to be able to recognise the difference;
- the fact that there are barriers of language and confidence that stand in the way of full involvement by many people from ethnic minority backgrounds, who may see meetings, forums, reports, a “Council” and so on as too formal or “official” in nature for them to take part comfortably, or at all;
- the need for extra support to overcome such barriers;
- the need for channels of access to the structure to be made as easy as possible, for example for the complaints service to have a phone line.

They stressed as much as anybody the need for the structure to be controlled from the bottom up. It was suggested that there should be a member or members from ethnic minorities on the governing body of
the SHC nationally. Locally, an ethnic minority forum might be a good idea.

**ROLE OF VOLUNTEERS**

The issue of the level of support that this structure will need from volunteers must also be addressed. It would be all too easy to assume that volunteers will be there to help. Volunteer fatigue must be addressed and acknowledgement of their role where appropriate must also be addressed.

**HEALTH COUNCIL ELECTIONS**

Chief executives observed that if the local offices of the proposed Scottish Health Council had elected members on their governing bodies, there would be a potential tension between them and the elected members of local authorities: both could purport to represent the public with an electoral mandate.
Conclusions and recommendations

This final section of the report draws some conclusions from the findings of the preceding sections about the implications for the way in which the consultation document is drafted.

1 CONTENT AND STYLE OF THE CONSULTATION

The pre-consultation exercise suggests that it is important that those responding have sufficient background to the consultation to be able to place the proposals in context. It would be useful in the consultation to set the context in terms of Our National Health, Patient Focus and Public Involvement and the range of initiatives, such as improvements in information provision, which will impact on how the NHS turns itself into a patient-centred organisation.

It is important that the consultation is presented in terms of the aims and objectives which it is hoped the proposed changes will achieve.

1.1 The wider context

There was general support in the pre-consultation for NHS boards having the primary responsibility for public involvement, although comments were made about the importance of making clear that this duty to involve the public extends throughout the NHS, at trust, practice and clinic level as well as at board level.

Patient Focus and Public Involvement

The pre-consultation focused on a specific issue, ie the proposed new structures for public involvement in the NHS. There was limited reference to the wider picture, for example the work currently being undertaken within the Scottish Executive by the Involving People team.
The need for NHS staff to be supported in their public involvement activity was mentioned by many of those consulted. The consultation document should set out clearly how the development of the capacity of the NHS to engage with the public will be supported, for example by the work currently being done by the Involving People team.

Other players
In addition there was no explicit reference to other bodies engaged in parallel agendas, for example the Clinical Standards Board for Scotland and its work on generic standards, which include an assessment of the extent to which service providers have involved their patients and the wider public. Options for ways in which the CSBS (or its proposed replacement the Quality and Standards Board for Scotland) could work with the proposed Scottish Health Council should be spelt out. For example, how should the QSBS be using the new body in its work, and would the new body have access to the work of the QSBS?

It is important that the consultation document sets the broader picture in terms of what is going on within the NHS to support public involvement and also in terms of the work of the Clinical Standards Board. This will be achieved in part if the structure of the consultation focuses on functions and roles, and shows the whole picture towards which the Scottish Executive is moving. It should also be made clear what the future role of the Involving People team is in relation to the proposed new structures.
1.2 Structure of the consultation

The consultation document should be structured in such a way as to set concrete proposals within the broader policy context, and to provide sufficient information about how the roles and functions which currently exist are expected to be delivered, for example through the work of the health councils.

Role and function

The pre-consultation was hampered by the limited knowledge and understanding of the role and functions of local health councils at present in Scotland. It would help to focus the consultation document if it presented the existing functions of health councils alongside an outline of how those functions would be carried out under the new system.

We would recommend that the Scottish Executive uses a format similar to that used in England in Annex A of the Involving Patients and the Public in Healthcare discussion document of September 2001. Health councils in Scotland have agreed a common set of six core objectives which 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.
At present it is assumed that these objectives are all valuable, and involve functions which should continue to be carried out in the future. It is therefore important that the consultation explains how these objectives would be achieved in any new structural arrangement.

For example, in relation to acting as a voice for patients and the public in the health council area, the consultation would set out the underlying principle that wherever possible it should be patients, patient organisations and communities who should speak directly to the NHS without the necessity of an intermediary, or representative. It should also outline the kind of circumstances in which it may still be necessary to have an organisation or organisations which speak on behalf of patients where it is not easy or possible for that group of patients to speak for themselves, for example patients who have used accident and emergency services on a single occasion. Equally, the argument might be made that in relation to a service like accident and emergency services, the role of any new structures might be to assist the NHS in designing methods to explore the experiences and views of those who have used services on a non-recurring basis.

1.3 Language

Another issue which the pre-consultation drew attention to was the importance of using language which most clearly expresses the intentions behind the proposals.

Language describing functions
The experience of the pre-consultation was that while there was general discussion of the proposed three functions of the new structures, i.e., development, assessment and feedback, there was some ambiguity about these words, and it might be helpful to reconsider whether these are the clearest words to use.
If, as suggested above, the structure of the consultation is built around functions, then proposals relating to the function of public representation, or being the voice of the public in relation to the health service, could be spelt out in terms of what the new bodies would be doing to support patients and the public in their involvement with the health service. The role of assessment would fall under a general heading of monitoring of NHS services, which would cover the role of the health council in assessing what their local NHS had been doing in terms of public involvement, but would also cover the allied role of the CSBS in monitoring the generic standards. The word “feedback” proved confusing - with a range of views as to what this implied.

**Representation**

Representation is a word noticeable for its absence from Patient Focus and Public Involvement. There is an implied principle in current work within the Scottish Executive that it is better to reduce the extent to which the dialogue with service users takes place through intermediaries claiming to represent the public, patients, or particular groups or communities, in favour of a more direct engagement with those patients or groups. There is no longer a desire or perceived need for a group which will represent patients or the public, but for an organisation which can support locally based groups and individuals in their engagement with service providers. Some of those consulted were keen to avoid having a body which “came between” the NHS and its patients.

While this is a commendable development, it will be important to acknowledge in the consultation document that there may be circumstances when some degree of representation is required, and when there may need to be alternative ways of engaging with particular groups of patients.
In addition, there will be a continuing demand from service providers and planners for patient or public representatives. It should be clearly acknowledged that use of such representatives is legitimate, and that it is important to consider how such representatives are selected and prepared for the role which they are being asked to play.

We would suggest therefore that the word “representation” should not be avoided, but should be addressed explicitly.

Honesty of language
Some confusion was caused in the pre-consultation by the continuing use of the term “health council” which led to a belief that no major change is intended to the existing structure of health councils. This was reflected in the view of health council members that they will still be there, with a similar job to do.

If it is considered desirable to continue to use the term “health council” because of difficulties associated with changing primary legislation, this should be made clear. It is important that the consultation makes clear that what is intended in the policy proposals is a radical change in the nature of the institutions to be known as health councils.

1.4 Scope and extent of consultation
In view of some dissatisfaction expressed during the pre-consultation about the limited time frame and limited opportunity to have informed input, it is important that the consultation:

• Is over an acceptable period of time, which in practice means that it conforms with Scottish Executive guidance on best practice in consultation
• Is targeted at as many relevant groupings as possible. For example, it suggested in the pre-consultation that Social Inclusion Partnerships which may be working on involving local communities should be included
• Engages proactively with groups which might otherwise be overlooked in a formal written consultation. This might involve organising a few groups or interviews with ethnic minority groups, homeless people, travellers etc

1.5 Feedback

The pre-consultation revealed a degree of cynicism about the impact of consultation, and there was an expressed desire to know what impact the pre-consultation and the consultation have on the policy proposals.

The consultation should acknowledge points which have come up during the pre-consultation, as many of the people involved in the pre-consultation will also be responding to the formal consultation.

2 THE NEW POLICY PROPOSALS

In addition to general recommendations about the style and content of the consultation document, the pre-consultation suggests that there are various issues which must be addressed clearly in the consultation document.

2.1 Exposition of the role of new bodies

There was a lack of clarity amongst those consulted during the pre-consultation about the proposals made in Patient Focus and Public Involvement, in particular in relation to the role and function of the new bodies. The proposed Scottish Health Council was perceived to be
a successor body to the Scottish Association of Health Councils, the local offices of the SHC were perceived as successors to local health councils, and the Health Service User Forum was little understood or appreciated. In order to get useful feedback from the consultation process it will be important to be much clearer about the nature and role of the proposed new bodies, and in how those differ from the existing structures.

Links between the Scottish Health Council and the local health service user forums
The intention of the Scottish Executive proposals in Patient Focus and Public Involvement that there should be a link between the professionally driven SHC and the grass roots based health service user forums was not understood. The majority of those involved in the pre-consultation were concerned with the practicalities of organising and running a forum which would potentially be very large, might be in danger of being dominated by vocal minority interests, and might be superimposed on existing forums, for example community care forums, and other patient or health forums organised at LHCC, trust or community level. At the same time, there was broad support for any new bodies being firmly rooted in local concerns. There was also a clear interest in the possibility of creating such forums, if the practical difficulties could be addressed.

In order to be clearer in the consultation document about how the link could be made between a professionally driven health council and the interests and concerns of local communities and local patients, one option would be to spell out how the local offices of the proposed health council would be required to relate to its 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

This approach would mean that there would not be a requirement to have a health service user forum in every health board area, but that it would be for the NHS board or for the proposed Scottish Health Council to decide how most effectively to engage the local community in the work of the new body.

The new bodies: functions, legitimacy and governance

Broadly speaking there are three sets of issues to be addressed: what the new bodies are being set up to do; how they gain legitimacy for what they do; and how they are governed.

Functions

This is the easiest to address, and could be achieved in part by presenting the consultation document in terms of the functions of the existing structures and relating these to the new proposals, as discussed above. It is important to be aware that there was a degree of resistance to what was perceived as a narrowing of the functions from those of existing health councils, and a dilution of their role as watchdog of the NHS in general.

It will be particularly important to be clear about the new role of the Scottish Health Council, i.e. that of assessing the performance of the NHS board in its public involvement activity. In relation to this, one point which was made by several people during the pre-consultation is the importance of this assessment extending beyond what local NHS services have done to involve the public, to the impact of that...
involvement on the service itself. It would also be useful to be clear about the relationship between what the SHC will be assessing and what the CSBS will be assessing.

The pre-consultation asked about the powers which the SHC should have. The answers to this question related to the range of functions which those consulted considered the SHC should have. For example, those who argued that the SHC should have a role as a watchdog with the power to raise any issue of local concern sought the power to monitor services, to require the NHS to provide information and to meet with the SHC, and to have the right to be consulted on service change.

Goverance
There was general agreement in the pre-consultation that the appointment of members of local health councils by health boards was a weakness of the existing system. Health councils were not perceived to be sufficiently independent of health boards, and they had no clear or direct links to the communities within which they operated. Health council members were considered by some to have no constituency, either in local communities or because their mandate derived from a particular patient group. Health council members did not agree with this critique, considering that their independence was not compromised by their relationship with the health board, and considering that they could act as legitimate voices for the public interest. The low level of awareness of health councils should, however, be borne in mind, in relation to these criticisms.

Legitimacy
This is linked to the question of governance, though not identical with it. Where bodies are democratically elected and answerable to a particular constituency they can derive the legitimacy of what they do
from that election. Where bodies are appointed, in whole or in part, or where the process of nomination involves intermediate organisations or processes, the bodies may seek legitimacy for what they do through the way in which they operate.

The Scottish Executive proposals clearly favour a national body - Scottish Health Council - with the local offices as the professional arms of the new body. However, there was widespread support in the pre-consultation for an organisation which is locally based with a degree of local autonomy about what issues it should be addressing and how. The legitimacy of what the local offices do is affected by the extent to which they are engaging 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? All these options were suggested in the pre-consultation.
- Independence of the SHC. There was broad support for the SHC being independent of the health service and of the Scottish Executive. 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 on page 5.
- An indication of resourcing and staffing levels in all three organisations

2.2 Implications of the proposals for staff

This was raised by existing health council staff, who are in favour of a smooth transition from the existing structures to the new proposals. There should be some indication in the consultation document about what will happen to existing staff, in terms of redeployment and training for any new skills required.

Concern was expressed by others in the pre-consultation that there are skills and experience within the present health councils which should not be lost in the transition to new structures. However, it is also important to note that if the primary function of health councils is to be the development and support of public involvement, there may be a need for staff with a different skill set from some existing staff, and here again the implications for staff and for staff training should follow from the functions which these staff will be required to fulfil.
2.3 Potential conflicts of interest

Questions about conflict of interest arose in the pre-consultation in relation to the different aspects of the roles of the proposed new structures. For example, it was suggested there might be a conflict of interest between the function of supporting and developing public involvement with the scrutiny of how well or effectively public involvement had been carried out.

Another potential conflict of interest existed 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.

2.4 Complaints and advocacy

The question of how people making complaints about the NHS would be supported was an area which was frequently raised during the pre-consultation. The NHS complaints procedure is currently under review, and it may be difficult to make clear proposals about this, but it is important that it is addressed in the consultation. Because the question of complaints was not addressed directly, there was a tendency in the pre-consultation to try to fit it in to one of the three functions listed, and it tended to be discussed in the context of the role of feedback, though clearly there is more to supporting complainants than providing feedback, and there is more to feedback than supporting complainants.
It is important to emphasise the need to make clear in the consultation document what is intended to happen in relation to complaints and advocacy.

It should be clearly stated 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. In the absence of any proposal for patient advice and support workers in hospitals, will there be any requirement on trusts, clinics or practices to have someone with a primary responsibility for customer care, with the goal of resolving potential complaints at an early stage?
- 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

It is possible to conceive a range of options in relation to complaints support (for example, that the NHS board, working with the local office of the SHC, should commission a complaint support service) and the proposals will need to reflect work being undertaken in relation to the review of the NHS complaints procedure, as well as the work associated with Patient Focus and Public Involvement.

Similarly, in relation to advocacy, it would be helpful for the consultation document to be clear about where the responsibility for providing advocacy services rests, and how members of the public can access such services.
3 RELATED ISSUES RAISED IN THE PRE-CONSULTATION

3.1 Public profile of new structures

The comment was made in the course of the pre-consultation that the new bodies should have a higher public profile than the health councils have at present. Once again the importance of the public profile of the new bodies will depend on the final decision about what their role and function should be. An organisation which primarily works to develop the capacity of patients and the public to engage with the NHS does not necessarily need a particularly high public profile. However, if there is to continue to be an organisation which has a role as a watchdog or monitor of the NHS on behalf of the public, it may be more important that it is recognised by the public. Whatever part of the new structure has a responsibility for supporting people in their complaints about the NHS may also need to have a high profile.

Name

To some extent this question is associated with the question of the name of the new bodies, and what message those names give to the public. For instance a body called Healthwatch has connotations of watchdog, and teeth, and is likely to appeal to those in favour of retaining this watchdog or monitoring role for the health council. Healthvoice suggests a less proactive body, more concerned with communication than with monitoring or scrutiny.

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.
3.2 The interface between health and other areas

This was raised in several groups, particularly the regional groups, with the view being expressed that it would be a mistake to create new bodies in the health sphere without taking account of links with social care. The related point was made that any new structures should build on similar structures already functioning in the social or community care spheres.

Some of those consulted also made the point that health bodies must work much more closely in the future with local authorities, in relation to social care, education and housing. Many local authorities are already working to create local service user forums and panels, and using a range of methods to involve their service users. It is important that in local areas these are built on rather than adding new bodies.
Appendix 1

The following is a full list of all those organisations that were invited to the regional discussion groups and indicated acceptance, area by area. A proportion were not able to attend, despite having accepted, and these are denoted by an asterisk.

**Argyll & Clyde**

Argyll & Clyde NHS board  
Arthritis Care Greenock Branch  
Diabetes Group Paisley  
Excema Scotland  
Helensburgh and Lomond District Community Care Forum  
Inverclyde Asthmatic Caring Group  
Inverclyde Council on Disability  
Inverclyde Patients' Forum, Greenock*  
Levern Valley LHCC  
Links Club (Enduring Mental Illness group), Rothesay  
Paisley LHCC*  
Phoenix Community Health Project, Greenock  
Renfrewshire Autistic Group

**Ayr & Arran**

Ayrshire & Arran Primary Healthcare Trust (2 invited, 1 attended)  
Ayrshire Cancer Support  
Bridge Project (Drugs and alcohol)*  
CASS, Ayr (Citizens' Advocacy Support Service)*  
East Ayrshire Carers Centre  
Fullarton Community Health House*  
Headway (Head injuries)  
North Ayrshire Community Forum*  
South Ayrshire Volunteer Stroke Service
The Hypermobility Syndrome Association
The Wisdom Project (People diagnosed in early stages of dementia, and over 65s' mental health problems)

Borders

Arthritis Care
Autism Support Group, Earlston
Borders Carers Centre*
Borders Disability Forum
Borders LHCC
Borders NHS board
Borders Voluntary Community Care Forum
Burnfoot Community Health Project
Chest, Heart & Stroke Scotland
MESS (ME Support Service)
Penumbra Youth Project
Scottish Borders Elderly Council

Dumfries & Galloway

Alzheimers Scotland, Dumfries
Cancer Network
Dumfries and Galloway Elderly Forum
Dumfries Coalition of Disabled People
Dumfries & Nithsdale LHCC*
ECHO Community Health Project*
MS Borders Action
PASS (People advisory and support service)
Stewartry LHCC
User/carer involvement, Mental Health, Dumfries
Wigtown Partnership for Health
Young Carers' Project

**Fife**

AFASIC (Association for Speech Impaired Children)*
Breath Easy, Fife (Respiratory diseases)
Dunfermline LHCC
East Neuk Communities Group
Fife Families Support Project (Mental health)*
League of Friends of Adamson Hospital
Macmillan Carers
ME Support Group
North East LHCC
Prostate Cancer Support Group
Queen Margaret's Hospital Patients' Council*
West Fife Community Health Project*

**Forth Valley**

Bo'ness Family Centre*
British Colostomy Association
Central Carers Association
Falkirk Voluntary Sector Community Care Forum
Forth Valley Advocacy Service
Forth Valley LHCC
Forth Valley Primary Care NHS Trust
Mental Health Forum, Larbert
Off the Record, Stirling* (Mental and physical well-being of young people)
Open Secret, Falkirk (Community Health Project)
Parkinson's Disease Society, Stirling Branch
Stirling Health & Wellbeing Alliance*
Grampian

Aberdeen Foyer* (Supported and accommodated young people)
Cornerstone community care, Aberdeen* (Adult Learning Difficulties)
Deeside LHCC
Grampian Primary Care NHS Trust
Grampian Society for the Blind*
Moray Voluntary Sector Care Forum
NE Eating Disorders Support Group
NHC Project, Moray
PHACE (Grampian Gay Men's Health Project)
VSA Carers Centre (Voluntary Services Association)
West Gerioch Community Council

Greater Glasgow

ABM LHCC
Action for Sick Children
CASE (Elderly stroke victims)
Centre for Independent Living, Glasgow
CSV Health Action* (Advocacy for black and ethnic minorities)
Cystic Fibrosis Association
Drumchapel Community Action Team*
Glasgow Council for Single Homeless*
Health Service Forum, SE
North Glasgow Community Health Project
Scottish Motor Neurone Disease Association
SW Glasgow LHCC
Highland

Age Concern
Community House, Invergordon*
DASH* (Physical disability organisation)
Health Developmental Coordination Disorder Group*
Helmsdale Action Group
Highland Community Care Forum
Highland House (Young carers organisation)
Highland NHS board
Highland Primary Care NHS Trust
HUG at Highland Community Carer Forum (Mental health/learning disability organisation)
Osteoporosis Society
Patient Participation Group Spean Bridge

Lanarkshire

Alzheimers Scotland, Motherwell
Clydesdale United
Hamilton LHCC
Lanarkshire Community Care Forum
Lanarkshire Elderly Forum
Lanarkshire Kidney Patients' Association
Motherwell LHCC
National Association for Crohns and Colitis*
PHACTS
Shelter Families Project
Shotts Getting Better Together Project
Tactent (Cancer support group)
Lothian

The Ark (Advocacy/support for the homeless)
Bridges Project (supports vulnerable young people)
Chest, Heart & Stroke Scotland*
Darroch Annexe (ethnic women organisation)*
Craigmillar Community Health Project
ELCA (Edinburgh and Lothians Council on Alcohol)
Midlothian Community Care Forum
Midlothian LHCC
Midlothian Surestart Stepping Forward* (Children's/parents' issues)
Midlothian Women's Aid
South Central Edinburgh LHCC
Waverley Trust (AIDS organisation)
West Lothian Epilepsy Resource Centre

Orkney

Community Care Forum
Crossroads Carers
Haey Hope Club (Elderly organisation)
MS Society
New Community Schools Project*
Orkney Alcohol Counselling and Advisory Service
Orkney Blide Trust (Mental health organisation)
Orkney Disability Forum*
Orkney Islands Council
Orkney Miscarriage Support Group
Orkney NHS board (2 invited, 1 attended)
Visual impairment Society
Voluntary Action Orkney
Shetland

Alcohol Advice Centre
Disability Shetland
Firth and Mossbank Family Centre
Islesburgh Community Centre (supports young people)*
Shetland Autistic Support Group
Shetland Branch, Scottish Pensioners' Association
Shetland Community Drugs Team
Shetland Hospitals and Community Friends
Shetland LHCC
Shetland Voluntary Care Forum
South Mainland Cancer Support Group

Tayside

Angus LHCC
Angus Mental Health Association
Community Care Forum
Community Health Development Project
Disability Services
Dundee Age Concern*
Dundee Heart Support Group
Dundee International Women's Centre*
Friends of ARMS Ltd* (MS support group)
Multiple Sclerosis Society*
Parent to Parent, Tayside (support to families of children with any kind of special needs)
Perth and Kinross LHCC*
Tayside Association for the Deaf
Western Isles

Breast Cancer Support Group*
Cearn's Community Development Project*
Community Care Forum
Harris Disability Group
League of Friends of Harris House (Elderly)
Lifestyle Centre (Drugs and alcohol counselling)
Newton and Sandwick Community Partnership*
Open Sesame Project (supports parents of children with special needs)

Volunteer Stroke Service
Western Isles Association for Mental Health*
Western Isles NHS board (2 invited)

The following is a full list of all those organisations that attended the national discussion groups.

National Asthma Campaign Scotland
Voluntary Health Scotland
MS Society
FPA Scotland
Breast Cancer Care
Chest Heart and Stroke
Diabetes UK Scotland
Scottish Association for Mental Health
Epilepsy Action Scotland
Princes Royal Trust for Carers
Deafblind Scotland
Scottish Pensioners Forum
Additional written submissions or comments were received from two chief executives and two NHS board chairs.

One of these was from Mr David Steel, chief executive of the Clinical Standards Board for Scotland, who raised particular points to do with the interface between the proposed Scottish Health Council and the Clinical Standards Board. These were followed up in a meeting between Mr Steel, Martyn Evans of the Scottish Consumer Council and Lyn Jones of Scottish Health Feedback. The discussion at that meeting is not covered in this report.

Additional written submissions or comments were received from the following health councils:

- Dumfries and Galloway
- Fife
- Forth Valley
- Grampian
- Greater Glasgow
- Highland
- Lothian
- Orkney
- Shetland
- Western Isles

In addition, John Heaton a member of Fife health council, sent in some personal comments.

The health council chief officers' Group followed up their discussion meeting with a paper produced collectively by the Group as a whole. Additional comments were sent in by;
Rosemary Hill, chief officer, Argyll and Clyde health council
Sheila McGoran, chief officer, Lanarkshire health council.

Regional groups

One person followed up participation in a group with written comments, one person who was unable to attend sent in comments, and one person who had heard of the meetings but not received an invitation telephoned and gave comments.

National groups

A representative of Scottish Community Care Forum gave her views by phone.