Health and Social Services Committee HSS-07-01(p.3)

Date:	**2 May 2001**
Venue:	**Committee Room 3, National Assembly for Wales**
Title:	**Modernising Patient Advocacy and Support**

Purpose:

1. To provide the Committee with options for the delivery of patient advocacy and support services, andensuring a stronger public voice in the NHS in Wales.

Summary and Action:

2. This paper:

- provides options for future patient advocacy and support; and
- identifies areas for further work.

and invites the Health and Social Services Committee to

- consider the options presented; and
- note the consultation exercise to take place in June to test the options

Timing

3. This paper is presented at the Committee's request.

Introduction

4. A key commitment in "Improving Health in Wales" is to give patients and the public more say in the running of NHS services. This means putting patients first and building a health service around their needs. It also involves the NHS in Wales working much more closely with patients, their families and carers, and the public to look for ways to improve services and to plan changes and developments in services. It also means an NHS which welcomes the lessons learnt from the experiences of patients and carers.

5. This means fashioning an NHS which will be driven by the views and active involvement of individuals and communities in the design, delivery and monitoring of health services.

6. To help take this forward, Community Health Councils, the communities "watchdog" on the NHS, will be retained in Wales to play a key role in involving the public. Their functions may need to be re-focused and their structure re-visited, but the aim should be to strengthen their ability to represent the interests of the public from an independent perspective.

7. A working group has developed proposals to make our Community Health Councils more effective. It has also come forward with suggestions to provide front-line help for patients when things go wrong, and independent advocacy and support for people who wish to make a complaint. And the group has made suggestions on how NHS organisations could more effectively engage patients and the public in decision making about the planning, delivery and monitoring of healthcare services.

8. Taken together, the group's proposals, which will now be going out to consultation, should ensure a stronger public voice in the NHS in Wales. And an NHS which actively works to meet the expectation of patients and the public.

Background

9. A Welsh Office consultation document "Involving the Public" was published in 1998 which sought views on how the NHS could increase the involvement of patients and the public in the design and delivery of health services. The document also put forward options for to enable Community Health Councils (CHCs) to take a more focussed role in the new NHS.

10. Feedback confirmed the benefits of seeking greater public and patient involvement and the important role that Community Health Councils and Local Health Groups could play in that process. While some progress has been made by changes to the structure of Community Health Councils and on-going work to develop a framework for a public involvement strategy for the NHS, other issues in the document remain largely unaddressed.

11. On 1 April 2000, a new structure of Community Health Council federations was established to encourage CHCs to work together on strategic issues across each federation area. A commitment was given to carry out an independent evaluation on how the different federations were working after 12-15 months of operation.

12. In July 2000, the English NHS Plan was published which, among other things, proposed the abolition of Community Health Councils in England and arrangements for establishing new patient advocacy/support services in each NHS trust together with other mechanisms to improve patient representation in the NHS. This provided an opportunity to widen the remit of a working group being formed to look afresh at the role and remit of Community Health Councils, so that it could explore and develop options for ways of delivering patient advocacy and support in Wales, look at wider issues of

public involvement and some of the themes that remained outstanding from the previous consultation.

Working Group

13. A working group was established on 6th October 2000. Its remit was "to 'develop options for delivering patient advocacy and support services, and ensuring a stronger public voice in the NHS in Wales, taking into account experience gained, results of innovation, and the agenda for modernisation and change in the NHS, and to make recommendations."

14. The group is led by an independent chairperson and includes representatives from the NHS, Welsh Local Government Association, Community Health Councils and voluntary groups.

15. The group's key tasks and membership are contained in the attached annexe

16. In developing options to put to the Assembly, the group agreed that they must:

- be centred on the needs of patients/public and not primarily the needs of the NHS
- be realistic and acceptable to both the public and the NHS
- take into account (but not be bound by) proposals in the English NHS Plan
- take into account (but not be bound by) proposals put forward by the Association of Welsh Community Health Councils for CHC future role and structure
- provide an indication of how much each option would cost
- consider the legislative powers that exists and what new powers might be needed to deliver the options
- be easily understood by the public (there is a commitment in "Improving Health in Wales" to consult on the proposals).

17. In developing options, the group also considered commitments set out in the NHS Plan for Wales to improve public and patient involvement in the NHS, together with emerging findings from the UK-wide review of the NHS complaints procedure.

Options

18. The working group has developed proposals which cover the following areas:

- Front-line help for patients - by the appointment of patient support officers in NHS hospitals and Local Health Groups.

- Complaints support and advocacy - through an independent advocacy service to help patients who wish to make a complaint against the NHS.

- Public Involvement / public information - by the establishment of patient/public involvement groups for NHS trusts and Local Health Groups.

- Community Health Councils - to determine core functions for all

CHCs and for the Association of Welsh Community Health Councils.

Front line help/support for patients

19. Being ill or in need of care is stressful. Health services can be intimidating. Even in the best run parts of the NHS, things can go wrong. Patients sometimes feel reluctant to complain for fear their treatment may suffer as a result. When things go wrong, patients want things sorted out quickly and efficiently on the spot, rather than the situation escalating into a formal complaint and positions becoming entrenched.

20. Many problems can be sorted out at the time, but patients need someone who is accessible to them and their families or carers and who can listen to their concerns and take action to resolve them. And we need to ensure that this help is provided across both primary and secondary care sectors.

21. The group recommends that a **Patient Support Officer** (with roles and responsibilities based on national standards) should be appointed in each major hospital to:

- help to resolve patients' problems and concerns quickly and efficiently;

- act as the visible contact point to enable patients and the public to easily access the new system of patient support;

- work with existing complaints managers to ensure that front-line staff are trained and supported in dealing with complaints; and

- provide support for patient representative groups.

22. Hospital based Patient Support Officers (or some similar title) should have direct access to the chief executive and senior staff to enable action to be taken so that problems are resolved quickly. This should not only help to reduce the number of formal complaints made but should provide a visible and easily accessible contact point for patients, their families and carers who have concerns. They could also act as

a reference point for information about trust services, and a referral point for patients / carers who want to make a formal complaint about the NHS.

23. The primary care setting poses a different problem, not least the impracticality of having a dedicated Patient Support Officer based at each FHS practice. However, it would be feasible to base an officer in each Local Health Group (or Community Health Council) to:

- provide support and advice to individual FHS practices about handling concerns and complaints;
- act as a point of contact for people who wish to make a complaint, but are reluctant to complain directly to the practice for fear of the consequences of continued access to care (a recommendation put forward in the NHS complaints evaluation report); and
- develop annual plans for public involvement and patient focus across the LHG area (a NHS Plan for Wales commitment).

24. It is important that there is confidence in the transparency of the approach and action to ensure that consistent standards for Patient Support Officers are adopted throughout Wales.

25. There are a number of ways this service could be provided and managed. Located in hospitals and Local Health Groups/Community Health Councils, Patient Support Officers could be:

a. employed by the host NHS trust or Local Health Group (or the trust could employ both hospital based and primary care based Patient Support Officers);
b. employed by the trust/Local Health Group but managed by Community Health Councils;
c. employed by Community Health Councils;
d. employed and managed by an independent body (but commissioned . by the NHS or local authority);
e. employed and managed by local authorities; or
f. employed and managed by the National Assembly for Wales.

26. On the basis that each post would cost c£30k (salary + associated expenses, including training), providing a dedicated Patient Support Officer in 20 major hospitals (with links to their local community hospitals) and 22 Local Health Groups would cost in the region of £1.26m. However, some hospitals on Wales already have similar services, and there should also be notional savings associated with an expected drop in the number of formal complaints which these staff will bring.

Complaints support and Advocacy

27. Advocacy is a term that has wide meaning and implications, but for the purpose of this paper, the term advocacy is used to describe assistance (not legal) for people who wish to make a formal complaint about care or treatment they have received from the NHS.

28. The Health and Social Care Bill (subject to it being enacted) will place a duty upon the Assembly to ensure that advocacy services (excluding legal services) are available for people making formal complaints through the NHS complaints procedures.

29. Sometimes the NHS fails to deliver services to the standard expected by patients. A frequent concern is not that these shortcomings arise but that patients have difficulty in getting their concerns addressed. It is often easier for a patient to give up rather than pursue a complaint through the system.

30. Patient Support Officers, based in hospitals, could help to resolve patients concerns on the spot and prevent many from escalating into formal complaints. But there will be times when patients need to rely on support which is totally independent of the NHS, to make perhaps a serious complaint against the NHS. When patients want to speak to someone outside the hospital or primary care practice, an independent complaints advocacy service should be made available which would:

- assist patients with the preparation of a complaint (for example, advising the patient about the complaints process and helping them to prepare their case);
- help the patient with the drafting of correspondence relating to the complaint;
- represent the patient at hearings and meetings relating to the complaint (or provide advice and assistance to enable them to represent themselves); and
- handle correspondence relating to the complaint on behalf of the patient concerned.

31. Community Health Councils have traditionally considered complaints advocacy to be a service they could deliver, if adequately resourced, although it has never been part of their statutory role. Some CHCs offer advocacy services although limited funding to do this means that there is no consistent standard of service across Wales. "Improving Health in Wales" commits the Assembly to implement patient advocacy services following consultation on the recommendations of the working group.

32. An independent advocacy service for complainants could be:

a. provided by Community Health Councils across Wales (who could link with local organisations, including local authorities, who provide more specialist advocacy). Close liaison will be needed between all organisations providing services to ensure that patients receive the appropriate package of support if it involves one or more agencies.
b. commissioned centrally by the National Assembly from a number of separate providers;
c. commissioned locally by NHS trusts and Local Health Groups; or;
d. provided by local authorities.

33. Additional resources would be required to fund this service and while the group has not been able to

cost all of the options presented in the time available, on the basis that Community Health Councils provided this service across Wales, extra resources of around £180k, (dependent on the final structure of Community Health Councils), would be required to fund 5-6 additional posts based on CHC federations. These, and any wider advocacy provision, would need to meet national accreditation and training standards mentioned below.

34. Then there is the wider issue of advocacy which is to provide assistance to, or represent, patients in any issue relating to the NHS, or to services jointly provided by health and social services. Finding your way through the care system can be a daunting experience for anyone. Most people who need care are able to speak for themselves, but many cannot for a wide variety of reasons. They may feel vulnerable and need help to express a view about decisions that affect their care. Independent advocacy services can provide this type of support. Members of the working group established that there are many kinds of advocacy services being delivered across Wales, but felt that there are also gaps in this provision. The Mental Health Strategy is already addressing one of these gaps.

35. Mapping this provision is in itself a large undertaking, even before moving on to evaluate the effectiveness of the various schemes. The working group felt that these issues should be given further consideration and recommended that the Committee may wish to commission a separate project, which could interface with other ongoing reviews in this area, to:

- scope the provision of existing advocacy services across Wales;
- evaluate their effectiveness;
- identify gaps in advocacy provision
- develop national standards, including the evaluation and accreditation of local advocacy services;
- identify the likely costs of moving from a fairly informal advocacy network to a more standardised and accountable advocacy system;
- recommend how to best provide national specialist advocacy services for the most disadvantaged, e.g. for people with mental health problems or communication difficulties, or for older people, children and young people;
- ensure training is provided to national standards; and
- ensure that all NHS and partner organisations use the information available from local advocacy networks to inform the strategic development of services.

Public Involvement

36. The Health and Social Care Bill (subject to it being enacted) will place a legal obligation on all NHS organisations to ensure that they effectively engage the public in decision making across the range of planning, delivering and monitoring of NHS services.

37. A key commitment in "Improving Health in Wales" is to give patients and the public more say in the running of NHS services. In addition to the development of a new complaints system (proposals will be going out to consultation), all trusts and Local Health Groups will be required to produce annual plans setting out their proposals for public involvement and patient focus. New guidance on formal consultation will be produced and Chief Executives will be held accountable for the effective implementation of public involvement activities within their organisations.

38. Mechanisms will need to be put in place to monitor and review NHS services, to obtain patients' views about those services, and to report on those views and what action is planned as a result. To take this forward, the group felt that that it is important to establish patient/public involvement groups for each NHS trust in Wales. Some trusts already have standing groups of patients/public to support them in their work. There are a number of tasks and roles which these groups could undertake in partnership with CHC's. They could:

- help trusts to develop their annual public involvement plans and monitor delivery;
- provide the patient/public perspective on the development and delivery of services;
- monitor feedback received from patient surveys, questionnaires or focus groups, and make recommendations for improvements to services;
- monitor and review services provided by the trust;
- monitor the consultation process for major service changes (with the option of carrying the consultation itself, if agreed by the chief executive/board);
- develop patient prospectuses;
- develop local charters, in partnership with CHCs and local authorities; and
- act as a conduit between the trust and the public to ensure that public/patients' views are at the heart of decision making.

39. Key questions need to be considered about the make up of these groups. For example:

- should they be "one-off" groups to consider one or more of the above proposed functions? Or should they have a longer life span?

- from where should their membership be drawn to ensure transparency and proper representation?

- what should their role and relationship be to CHCs? For example, should they be supported and serviced by CHCs?

40. The make up, and operational arrangements for these groups could be considered in detail through the planned consultation exercise.

Public Information

41. The working group felt that there should be a general duty placed on all NHS organisations dealing with the public to provide information about services. This should be addressed through the publication of an annual prospectus by every NHS trust and Local Health Group, as flagged in "Improving Health in Wales".

42. The group was also concerned about the provision of a national health information service to provide information on local and national self-help groups, common diseases, conditions and treatment and healthy lifestyle information. It recognised that NHS Direct had only been in operation for a year or so but felt it could play a wider role in relation to the provision of wider health information, in partnership with CHCs and the NHS. The group also recognised the important role played by specialist helplines (e. g. the rural stress helpline) and the value users place on them.

Community Health Councils

43. A key task of the group was to examine whether the remit of Community Health Councils might be widened to make them more effective and representative; the role they might play in the NHS complaints procedure, and what membership changes might be put in place.

44. Community Health Councils have been in existence for 25 years and have done much to contribute positively to the development of improved services and standards across NHS Wales. But there are variations in the way that CHCs work and the impact that they have on the community and the NHS. In Wales there have been recent changes to CHCs to provide them with extra support and a stronger voice by forming groups of CHCs into federations. This is intended to provide greater help to the individual CHC, enable them to develop common standards, share skills, information and best practice, and develop a more strategic influence for the NHS in Wales. By contrast, in England, Community Health Councils are to be abolished in the next two years and replaced by separate bodies.

45. CHCs' strengths lie in their statutory status and their ability to represent the interests of the public, free from any vested interest. It is this role the Assembly wants to see strengthened. Community Health Councils need to work together so that the voice of the Welsh public influences policy rather than reacting to it. The role of Community Health Councils is to focus on the wider picture. This could usefully be done by using existing networks within the community.

46. The group felt that Community Health Councils should remain, but their roles and responsibilities should be refocused, their structure revisited, and their performance and accountability made clearer. It was also felt that Community Health Council membership still needed further review subject to legislative opportunity.

47. On the issue of the structure of Community Health Councils, the group felt that the proposed independent evaluation of the Community Health Council federation models should go ahead. This review will be completed by September 2001.

48. In terms of the core activities of Community Health Councils, the group recommended that these should be to:

- monitor and review the provision of NHS services;
- respond to proposals for major service change;
- provide an independent advocacy service for complainants (with links to other organisations for the delivery of specialist advocacy support);
- maintain an overview of the operation of the NHS complaints procedures and monitor action taken in response to complaints;
- provide an inspection function into primary care and other areas where NHS purchased services are delivered; e.g. private nursing homes (with secondary care inspections carried out in partnership with public/patient involvement groups);
- monitor public involvement activities of NHS bodies in their area;
- provide advice and guidance on initiatives to involve the public on particular issues; and
- carry out public involvement exercises at the request of other organisations.

49. Concentrating CHC resources on these activities will result in a greater degree of consistency and effectiveness in the service provided to the public and greater potential for all Wales views on issues to come forward. The NHS is a large and complex organisation and it is vital that we obtain Wales wide views on important issues that affect the public.

50. Many of the above activities can be achieved through existing legislation. Others such as the proposed extension of inspection powers into primary care and private nursing home settings, will require new legislation. The additional legislative requirements have been identified in the proposals for

a Welsh Health and Well-Being Bill. In the meantime, the need for all patients receiving NHS funded treatment in a private establishment to be inspected by the CHC should be enforced by including a requirement into the contract between the NHS and the independent provider.

Association of Welsh Community Health Councils

51. As a result of the abolition of Community Health Councils in England, the "umbrella" body for CHCs in England and Wales (ACHCEW) will also be abolished. ACHCEW currently provides legal advice and information services to Community Health Councils in Wales as well as being a forum to share concerns and good practice. We need to consider how these services might best be provided in the future, together with any changes to the role and future direction of the Association of Welsh Community Health Councils.

52. The working group felt that the Association should:

- provide a strategic link for partnership working with the Assembly;
- undertake projects for the Assembly where an all-Wales picture is required;
- set performance standards for CHC service delivery across Wales;
- review the activity and performance of Community Health Councils
- provide a research facility for Community Health Councils;
- with the Assembly, consider complaints against Community Health Councils; and
- provide support, guidance and advice for Community Health Councils on all aspects of their functions.

53. Consideration also needs to be given to whether the Association should be established as a statutory or non-statutory body. This issue will be considered as part of the review of the Community Health Councils

Conclusion

54. The transition from the current simple, although limited, model of patient representation and public involvement to a more wide-ranging and powerful system will bring real benefit for patients and the public. These suggestions will ensure:

- fast and appropriate support for patients where and when they need it;

- independent and objective support when patients want it;

- real influence for patients and the public at every level of the health service;
- public and patient involvement in the future development of health services; and

- for the first time ever, a NHS with a statutory duty to seek the views of its users.

Consultation

55. The Assembly will consult with all key stakeholders on the options presented through a series of 10 workshop / conference sessions to be held across Wales. Five of these will concentrate on the views of the public, with the remaining sessions arranged for other key stakeholders including the NHS, local government, voluntary sector and patient organisations. The results will be reported to the committee at it's meeting on 18th July.

Finance

56. The consultation exercise is expected to cost £10k, which will be funded through the Department's existing public involvement budget of £129k.

57. The costs of implementing any changes will be dependent on the outcome of the consultation exercise and what changes the Assembly decide to take forward. Recommendations will come forward to you in July, following an analysis of the consultation results and any financial implications will be considered as part of the Budget Planning Round.

Compliance

58. The establishment of Patient Liaison Services and Patient Participation Groups could be delivered using existing powers to issue directions using section 17 of the NHS Act 1977.

59. Section 20 of, and Schedule 7 to the NHS Act 1977 provide for regulations to be made by the Secretary of State to bring forward regulations in connection with the operation of CHCs. The majority of changes proposed to modernise CHCs could be facilitated using these regulation making powers.

60. These powers have been transferred to the Assembly under the Transfer of Functions Order and have been delegated as part of the Minister for Health and Social Services portfolio, by the First Minister.

61. The remaining issues relating to the reform of CHCs, would require changes to primary legislation. These are the:

- change of name

- change of membership arrangements
- extension of powers into primary care and private nursing homes would need primary legislation

62. We are seeking these opportunities through the proposed Health and Well Being Bill currently being drafted.

Action for Committee

63. The Committee is invited to:

- consider the options presented; and

- note the consultation exercise to take place in June, (previously agreed to by party spokespersons,) to test the options, with the results brought back to the Committee in July.

Jane Hutt

Minister for Health and Social Services

Annexe

MODERNISING PATIENT ADVOCACY/SUPPORT AND PUBLIC LIAISON

Terms of Reference

The group will have the following terms of reference:

"To develop options for delivering patient advocacy and support services, and ensuring a stronger public voice in the NHS in Wales, taking into account experience gained, results of innovation, and the agenda for modernisation and change in the NHS, and to make recommendations"

Tasks

Taking into account the wider strategic remit above (including proposals to develop a strategy for involving the public), the group's tasks will be to:

- consider how best to ensure effective public liaison and a stronger public voice in the development, provision and delivery of NHS services;

- examine current mechanisms of patient advocacy and support provided by the NHS and other organisations, including Community Health Councils (CHCs), and evaluate their effectiveness;

- consider proposals for patient advocacy and liaison set out in the English NHS Plan, and their appropriateness to Wales;

- examine whether the remit of Community Health Councils in Wales might be widened to make them more effective and representative; for example the role they might play in the NHS complaints procedure, and what membership changes might be put in place;

- examine the current system for consultation and referral of service change proposals, their effectiveness and how they might be changed to ensure better ways of engaging with and responding to public and user views;

- examine the current methods used to inspect NHS premises and consider how these may be changed to ensure consistent and robust standards, reporting and follow-up arrangements; and
- present options for delivering patient advocacy and support services, and ensuring a stronger public voice in the NHS in Wales; and make recommendations for an independent consultation exercise to seek the views of patients/public and other key stakeholders.

Membership of Group

Led by an independent chairman, the group's membership will be drawn from:

Health Authority (1)

NHS Trust (2)

Local Health Group (2)

Welsh Local Government Association (1)

Community Health Councils (3)

Patients' Association (1)

National Carers Forum (1)

Welsh Consumer Council (1)

Wales Council for Voluntary Action (1)

Patient/Lay representative (1)

National Assembly (2)

Welsh Assembly representatives from other divisions e.g. Human Resources Division (CHC membership issues), Health Service Strategy (service changes) and Legal will be co-opted as and when necessary.