HEALTH NEWS BRIEFING

ASSOCIATION OF COMMUNITY HEALTH
COUNCILS FOR ENGLAND AND WALES

CHCs and the New NHS:

ACHCEW's response to the White Papers for the NHS in England and Wales.

May 1998

SUMMARY

The Government published two White Papers setting out their plans for the NHS in England and Wales; "*The New NHS: Modern - Dependable*" and *"NHS Wales - putting patients first"*. This Health News Briefing sets out the response from the Association of Community Health Councils for England and Wales (ACHCEW) as adopted at a Special General Meeting on 27 April 1998.

The key points of the White Papers are summarised and examined from a CHC and patients' perspective. The recommendations are summarised at the end of the briefing.

The emphasis on partnerships and the plan to end the internal market and GP Fundholding are broadly welcomed. However we are disappointed that the White Papers do not plan stronger mechanisms to ensure that the needs and expectations of patients are heard: The briefing calls for a national working group, which is led by CHCs and other user and carer representative organisations and with representation from the NHSE, to be established to develop national guidance/ national frameworks for public involvement and consultation.

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1. Introduction

The new White Paper on the NHS in England; *"The New NHS: Modern - Dependable"*, talks of a third way forward for the NHS: not a return to the old centralised command and control model of the 1970s nor a continuation of the internal market model of the 1990s. The White Paper will keep the separation of the planning of hospital care and its provision but will abolish the internal market.

It talks of six principles that will guide the changes:

a) Renewing the NHS as a genuinely national service.

b) Making the delivery of health care against new national standards a matter of local responsibility.

c) Getting the NHS to work in partnership.

d) Improving efficiency so that every pound in the NHS is spent to maximise the care for patients.

e) Shifting the focus on to quality of care so that excellence is guaranteed to all patients.

f) Rebuilding public confidence in the NHS.

The White Paper for Wales: *"NHS Wales - putting patients first"*, also talks of discarding what has failed whilst keeping what works. In Wales too the separation of planning of hospital care and its provision will be kept whilst abolishing the internal market. There are common themes and many of the proposals are similar to the English White Paper.

The Welsh White Paper has seven values that the NHS in Wales will be expected to focus on:

a) Fairness - patients should have access to treatment and services according to their clinical need.

b) Effectiveness - treatment should reflect the most up-to-date scientific evidence and clinical practice.

c) Efficiency - NHS Wales should achieve best value in its use of resources.

d) Responsiveness - services should be designed with the needs of the individual patients in mind.

e) Integration - NHS Wales and other organisations should work together to deliver integrated packages of care for each patient.

f) Accountability - NHS Wales should be more accountable to people.

g) Flexibility - services should be flexible enough to meet local needs, while also delivering wider improvements in health.

The Welsh Assembly will assume responsibility for overseeing the NHS in Wales and will have responsibility of allocating resources to health from its overall budget.

Following implementation of the 1990 NHS and Community Care Act, the Health Service saw the introduction of the internal market, with the separation of the purchasing and providing functions; the creation of self governing NHS Trusts and GP fundholding practices. The Government of the time argued that such changes would move decision making away from the centre making service delivery more responsive and directly accountable to patients.

The 1990 Act reduced the size of District Health Authority Boards to a chair (appointed by the Secretary of State), five non executive members (appointed by the regional health authority) and five executive members. The effect of such changes was to increase the power of senior managers, whilst effectively making the non-executive members accountable, not to the local community, but to the regional health authorities. The new White Papers appear to again be shifting the balance of power - but this time in the direction of General Practitioners. Whilst ACHCEW broadly welcomes many of the initiatives contained within the White papers we are concerned about the tendency towards increased professional domination of the NHS and the extent to which GPs are used as proxies for patients. GPs function as providers as well as purchasers of care. This should be acknowledged and subject to open audit.

GP fundholding reduced the public's ability to see how decisions are reached in the NHS. Fundholding practices do not have to consult with the local population about what services they purchase. Many CHCs are frustrated in their efforts to be consulted; indeed ACHCEW found that most CHCs had never been informed of fundholders' plans for purchasing health care for their patients. We are pleased therefore to see the commitment to ending GP fundholding and the creation of Primary Care Groups in England and Local Health Groups in Wales. However CHCs still require increased statutory rights if they are to be able to properly represent users in the primary care sector.

CHCs only get one explicit mention in the English White Paper where it states that "the Government wants a strong public voice in health and healthcare-decision making, recognising the important part played by Community Health Councils in providing information and advice and in representing the patient's interests." ACHCEW is pleased to see the Government acknowledging the important role played by CHCs. However we are disappointed that the document does not plan stronger mechanisms to

ensure that the needs and expectations of patients are heard. The document talks of partnership without giving much detail as to how this will happen and without mentioning CHCs as one of the partners.

CHCs are mentioned more often in the Welsh White Paper but each time they are mentioned they are hedged around with caveats and "other options" for engaging the public. Indeed the document states: "This White Paper provides an opportunity to look at arrangements for public involvement and the roles and responsibilities of CHCs. The simple status quo would be inconsistent with the changes being introduced elsewhere and would be a lost opportunity to develop relevant leverage for patients and communities in the new settings."

2. Health Authorities

2.1 Ending the internal market

Both White Papers replace the internal market with "integrated care". In England care will be commissioned through three or five year service agreements by some 500 consortiums of primary care professionals known as Primary Care Groups.

In Wales care will be commissioned by similar groups to be known as Local Health Groups. However the separation of the planning of hospital care and its provision has been retained.

ACHCEW welcomes this end of the internal market which encouraged hospital to compete against hospital and community service against community service. This has resulted in both rising bureaucratic costs and inequity of service provision.

2.2 Health Improvement Programmes

Health authorities are to have a new focus on improving health by drawing up Health Improvement Programmes (HIPs) - the local strategy for improving health and healthcare, drawn up in consultation with NHS Trusts, Primary Care Groups/Local Health Groups, other primary care professionals such as dentists, opticians and pharmacists and other partner organisations.

In England the Health Improvement Programmes will cover a three year period and it is envisaged that the first of them will be in place by April 1999. Whilst in Wales they will set out a clear agenda for the first three years and indicate broad intentions for the fourth and fifth years. The new Health Improvement Programmes should provide a planning framework that has been missing for some years and are broadly welcomed by ACHCEW.

However neither White Paper explicitly mentions CHCs in the context of Health Improvement Programmes. ACHCEW believes that, with their statutory duty to represent the interests in the health service of the public in their district, CHCs should play a significant role in this process. CHCs should be formally consulted on HIPs and involved at an early stage, and in an advisory capacity, in the development of HIPs.

However, the extent to which the Health Improvement Programmes will detail service provision is less clear: the English White Paper simply states that they will cover "the range, location and investment required in local health services to meet the needs of

local people" while the Welsh Paper goes further with: "comprehensive action plans to improve the health of local people across a range of health gain areas."

The direct responsibility for commissioning of care will eventually be devolved to the Primary Care Groups/Local Health Groups - with health authorities allocating resources and holding them to account.

The English White Paper acknowledges that economic, social and environmental factors affect people's health. We are pleased to see a statutory duty being placed upon health authorities and local authorities to work together for the common good. However we are acutely aware that without increased funding it may prove difficult for many local authorities to make significant changes to the economic, social and environmental factors that affect people's health.

CHCs should be able to play a key role in this partnership between health authorities and local authorities as half the membership of CHCs is chosen by local authorities (with an additional one third from the voluntary sector and the remainder appointed by the Secretary of State for Health).

ACHCEW was disappointed that in outlining Health Improvement Programmes the White Papers made no mention of "hard to reach groups" such as black and ethnic minorities and people with learning difficulties. We believe that the Health Improvement Programmes offer an ideal opportunity for health authorities to outline explicit measures they propose to take to reach such groups and improve their health. Based in the local community CHCs would be ideally placed to work in partnership with the health authority in helping identify the health needs of these disadvantaged groups.

2.3 Mergers of Health Authorities and the implications for CHCs

The English White Paper indicates that the number of health authorities will reduce. It is felt that the number could reduce to as few as forty. In Wales the Assembly will have powers to review the number of health authorities. ACHCEW's position is that where health authorities merge, the presumption must be that the CHCs involved will not merge. CHCs covering large geographical areas would be too remote from identifiable communities perceived by the local people to be identifiable areas.

The first priority of the Secretary of State should be to ensure that the local communities involved are effectively represented. CHCs should only be merged where it is clear that the local communities would be more effectively represented by a merged CHC and where all the CHCs concerned agree that this is appropriate.

3 Primary Care

Primary Care Groups in England and Local Health Groups in Wales are to commission health services for their population from relevant NHS Trusts, within the framework of the Health Improvement Programme.

While the White Papers emphasise the increased role of the primary care professions in the development and planning of services they are not overly prescriptive of the structure of the Groups - the English White Paper stating: "successful local arrangements will be built upon, and not discarded. The approach will be bottom-up and developmental."

In England four possible models of Primary Care Groups are set out including Primary Care Trusts able to directly run community hospitals and community health services. Each Primary Care Group will have available their population's share of the available resources for hospital and community health services, prescribing and general practice infrastructure.

In Wales the Local Health Groups will bring together GP Practices, other health care professionals and (more explicitly than in the English White Paper) social service departments and voluntary organisations. Like their English counterparts the Local Health Groups will have their populations share of the available resources for hospital and community health services, prescribing and general practice infrastructure.

It would appear that peer pressure within the Group will be the incentive to promote efficient use of resources.

ACHCEW has been critical of the lack of accountability of GP fundholding practices. Given that the new Primary Care Groups may resemble the current "multi funds" or "total purchasing projects" it is unclear how the new groups will be any more accountable.

The English White Paper states that Primary Care Groups will be "accountable to Health Authorities for the way they discharge their functions, including financial matters" and that they are required to "have clear arrangements for public involvement including open meetings". The Welsh White Paper is better, stating that each Local Health Group will: "make clear arrangements to involve, consult and respond to the local community and to better integrate the delivery of primary and community health services."

However ACHCEW is concerned about the lack of rights for CHCs to represent patients' views at this level.

It would appear the commissioning of health care will be driven by the primary care professions - the English White Paper stating that "Quality standards, service protocols

and agreements should be set by direct discussion between clinicians to ensure primary and secondary care services are properly integrated and programmes of care developed to reflect patients needs". Just how patients will input into this process is not stated.

CHCs are in a unique position to contribute to Primary Care /Local Health Groups' commissioning decisions and will need to develop relationships with these Groups.

ACHCEW would expect Primary Care /Local Health Groups to hold public meetings and to consult locally about their plans.

In preparing legislation to establish Primary Care Groups the Government must ensure that health authorities have reserve powers to take over the management of Primary Care Groups should they fail.

CHCs should have a legal, explicit right to be consulted on all significant changes to commissioning intentions of the Primary Care/Local Health Groups and any other primary care providers such as dentists, opticians and pharmacists.

We would also expect Primary Care/Local Health Groups to operate openly and involve the local community in all decision making processes about the care to be commissioned. Special emphasis should be placed on ensuring that the views of "hard to reach groups" (such as black and ethnic minority communities and people with learning difficulties) are taken into account.

CHCs should be given speaking observer status on the Primary Care/Local Health Groups' governing bodies and have a right to enter and inspect all Group premises and any other sites where NHS primary care services are delivered.

Results of health authority audits or reviews of Primary Care/Local Health Groups should be made available to CHCs.

Primary Care/Local Health Groups should comply with the requirements laid down in the *Code of Practice on Openness in the NHS*.

Experiences of GP fundholding raised particular issues about accountability. ACHCEW found that many fundholders failed to comply with circulars from the Department of Health in relation to sharing information. Bearing this previous experience in mind:

ACHCEW believes that:

a) Health authorities should be required to publish annual summaries of Primary Care/Local Health Group Performance.

b) Primary Care/Local Health Groups should set out in their published performance reports, the contact they have had with CHCs and the steps they

have taken to involve patients in service planning, including measures such as the use of surveys and the establishment of Patient Participation Groups.

c) The performance reports should also specify the lessons which have been learned from patient complaints. Practice based complaints systems must be a mechanism for airing and addressing problems, not for smothering them.

4 NHS Trusts

Trusts will be required to work in partnership with other NHS organisations and they will be required to participate in the development of the Health Improvement Programmes. Increased "partnership" could result in some hospitals merging as services are rationalised on one site. However the English White Paper states that mergers of community and acute trusts will not be encouraged and: "Nor will amalgamation of smaller community NHS Trusts be encouraged if this inhibits closer working with local primary care teams".

The Welsh White Paper states that there will be reconfiguration of Trusts in April 1999 as the "current configuration of Trusts is haphazard and not well placed to deliver effective health care in the most efficient manner in the new non-market NHS". A formal consultation process will take place over the summer of 1998.

There is an emphasis on improving quality with the concept of clinical governance introduced requiring practitioners to accept responsibility for developing and maintaining standards: The English White Paper explicitly stating that legislation will be introduced giving Trusts a statutory duty for ensuring quality standards are met. Trusts are to be accountable to their NHS Executive regional office not only for financial performance but also for maintaining clinical standards.

The White Papers reiterate the Government's commitment that Trusts are to hold board meetings in public and that Boards will be more representative of the local community. They also state that no management information in the future will be classified as 'commercial in confidence' between NHS bodies.

CHCs were concerned that Trusts were only required to hold their Annual General Meetings in public. Whilst welcoming the requirement that Trust Boards should hold all their meetings in public, ACHCEW is still concerned as to whether decisions will really be made in public or whether the real decision making will take place "behind closed doors".

ACHCEW welcomes this greater openness of Trusts but believes that CHCs should have a right to participate (but not vote) at Board meetings.

It should be a legal duty of Trusts to provide CHCs with such information about the planning and operation of health services in its area as the CHC may reasonably require in order to discharge its functions.

Trusts should be legally obliged to consult CHCs about substantial developments or substantial variations in service delivery.

Detailed information about the planning and operations of Trusts should be available to CHCs and full business plans should be published.

5 Specialist Services

The English White Paper states that the commissioning of specialist services for populations larger than that of a single health authority but below the level covered by the existing National Specialist Commissioning Advisory Group will become the responsibility of the NHS regional executive offices.

There is no explicit mechanism for the involvement of CHCs although the White Paper does state that "the NHS Executive will involve users and carers in its own work programme". ACHCEW would like to see a mechanism for directly involving patients in this process.

6 Quality Standards

6.1 National Service Frameworks

Evidence based National Service Frameworks will be introduced setting out the patterns and levels of service which should be provided for patients. CHCs are aware of variation in service delivery around the country and measures such as these to ensure improved quality are a positive step. The Welsh White Paper indicates that the first National Service Framework to be introduced in Wales will be one for cervical screening - to be produced during 1998.

National Service Frameworks have the potential to bring up the level and quality of service in poorly provided areas. They could reduce, even eliminate, the regional variations in the structures of service delivery and referral patterns.

However it appears that they could also be used to recommend that certain forms of treatment are not made available. ACHCEW would like reassurances that they will not be used to deny any effective forms of treatment to people who could benefit.

6.2 National Institute for Clinical Excellence

A National Institute for Clinical Excellence (NICE) will disseminate guidelines on clinical and cost effectiveness. However the final role of the Institute is still unclear as the English White Paper states: "The Government will consider developing the role and functions of the National Institute as it gathers momentum and experience".

Membership of the Institute will be drawn from the health professions, the NHS, academics, health economists and patients' interests. However it does not expand further as to how patients' interests will be represented.

As the statutory national body representing CHCs, ACHCEW would be ideally placed to represent patients' interests on NICE.

6.3 Commission for Health Improvement

A Commission for Health Improvement will be established to oversee clinical governance. It will offer an independent guarantee that local systems to monitor, measure and improve clinical quality are in place and will be able to intervene on the

direction of the Secretary of State or by invitation from Primary Care Groups, health authorities and NHS Trusts.

ACHCEW would like to see CHCs on this list of organisations that are able to invite the Commission to investigate.

7 Fairness and efficiency

The internal market was the mechanism that was supposed to make the NHS more efficient. The White Papers propose new mechanisms to improve performance.

Resources are to be "fairly" distributed through health authorities to the Primary Care Groups and clinical and financial responsibility are to be aligned allowing clinicians to influence the use of resources.

Management costs are to be capped and bureaucracy reduced. Measures that improve the use of resources available to the NHS are to be welcomed.

However ACHCEW believes that NHS services are in huge demand and increased resources are needed if service provision, already badly stretched, is to be maintained.

7.1 National Reference Costs

The old Purchaser Efficiency Index will be phased out and replaced by a new schedule of National Reference Costs which will itemise the cost of individual treatments across the NHS.

ACHCEW is concerned that this could lead to a more explicit rationing that should only take place following public consultation.

8 Specific measures

The English White Paper proposes a 24 Hour nurse-led helpline with the whole country covered by 2000.

Whilst welcoming the helpline as an innovative idea ACHCEW would like clarification as to how the helpline will relate to the existing NHS Information-line; a reassurance that it will be a freephone number so as not to deter those on low incomes from using it; a reassurance that people living in Wales will have access to the service (the Welsh White Paper makes no mention of the service).

The English White Paper promises new technology to link every GP surgery and hospital to the NHSnet by 2002. Whilst the Welsh White Paper talks of a "secure telecommunications network".

The NHS clearly needs to keep abreast of new technology. However ACHCEW believes that patient confidentiality is of paramount importance and any system proposed must satisfy stringent confidentiality requirements.

The English White Paper promises guaranteed referral to a specialist within two weeks for anyone suspected of having cancer; whilst the Welsh White Paper promises "everyone with suspected breast cancer will be seen by the hospital's breast team within five working days of receipt of their GP's request that they should be seen urgently".

Whilst cautiously welcoming these commitments to speed the referral to specialists, ACHCEW has reservations. We are concerned that it could lead to increased diagnosis of cancer without making it possible to treat these increased numbers. Patients could be fast tracked to a specialist only to find that there is then a waiting list for treatment. ACHCEW would like to see a commitment that this will not happen as it is a nonsense to fund rapid referral without providing the means to deliver the required treatment to those who have been referred.

9 Patients, CHCs and the new NHS

The White Papers promise the first ever national patient survey. A national patient survey could show a systematic effort to listen to patients' concerns and especially those whose views are not always heard. But we are concerned that it could become a "tick box" exercise that fails to elicit the real views of patients about the NHS. A national patients' survey has the potential to be a useful exercise but it is important to have the survey properly validated by CHCs and other patients' organisations, before it is used.

The commitment to a new NHS Charter is also reiterated. ACHCEW is represented on the committee that has been set up to examine this. ACHCEW welcomes the review. The existing Charter has improved NHS services but significant gaps undermine patients' access to health care, quality of treatment and real choice. In 1996, ACHCEW launched its own *Patients' Agenda* which highlights areas where patients rights are poor or non-existent. *The Patients' Agenda* sets out new and stronger rights to address these issues.

Proposals in the *Patients' Agenda* include:

- An automatic right to a second opinion from a GP or consultant to strengthen patient choice.
- A right to an explanation if removed from or refused access to a GP's list.
- A right to free eye tests and dental check-ups.
- Rights to protect patient confidentiality and give people more control over their personal health information.

ACHCEW believes that patients' rights should be strengthened and in doing so make the NHS more accountable to the individual patient. We would like to see consideration of the rights contained in our *Patients' Agenda*.

CHCs play a vital role in ensuring that the NHS is accountable to both the individual patient and the wider community. ACHCEW has recently set out seven key principles to make CHCs effective in this role. CHCs need to:

a) Be independent of local NHS management;

b) Work in partnership with all purchasers, providers and the community;

c) Listen and consult with users and potential users;

d) Be proactive in seeking views of people who are not normally represented;

e) Be open to public scrutiny in their discussion and activities;

f) Be visible in and participate in relevant community activities; and

g) Provide user-responsive information and advice.

The Association also believes that CHCs are under resourced for the work that they currently do. To help CHCs ensure more accountability in the NHS, extra resources are needed. ACHCEW is particularly concerned about the situation in Wales where resources and staffing levels are lower than those in England.

10 Conclusion

The Government's White Papers on the NHS are broadly welcomed by the Association of Community Health Councils for England and Wales.

We welcome steps towards the setting of national standards for health care. In a National Health Service, patients do not expect the availability and the standards of care to depend on where they live or who purchases their treatment.

It is quite right that primary care professionals should play a big role in planning local services. We welcome the more inclusive approach of commissioning since fundholding has been unfair, bureaucratic and unaccountable. However it is not clear how the new Primary Care Groups will involve CHCs and other representatives of patients and we are concerned that GPs are viewed as proxies for patients.

We welcome the emphasis on partnership and hope that the reality proves as good as the rhetoric. We are concerned that when listing the "partners" the White Papers consistently fail to mention CHCs. ACHCEW would like to see the further consultation documents clearly stating the role of CHCs with their statutory duty to represent the interests in the health service of the public in their district.

Furthermore as the statutory representatives of patients CHCs may at times find that they are unable to agree with the views or actions of health authorities, NHS Trusts or the new Primary Care Groups. To be able to take an opposing point of view must be seen as part of a healthy partnership.

Above all, patients must be put first - their needs, their expectations and their choices. We are disappointed that stronger mechanisms are not proposed to ensure that this happens but we hope that a new spirit of partnership and openness will prevail.

The new White Papers present many opportunities for CHCs to demonstrate the unique contribution they are able to make in representing the views of patients and the local community. CHCs will need to be proactive in forging partnerships with the Primary Care Groups, NHS Trusts and health authorities, and it may be necessary to amend the statutory regulations to enable them to carry out their new roles effectively.

A national working group, which is led by CHCs and other user and carer representative organisations and with representation from the NHSE, should be established to develop national guidance / a national framework for public involvement and consultation. The guidance could pull together existing guidance, best practice and examples of public involvement which already exist.

11 Summary of recommendations

ACHCEW broadly welcomes many of the initiatives contained within the White Papers; *The New NHS: Modern and Dependable*; and *Putting Patients First: The Future of the NHS in Wales.*

We welcome the end of the internal market and are pleased to see the commitment to end GP Fundholding and the creation of Primary Care Groups in England and Local Health Groups in Wales.

We are concerned about the tendency towards increased professional domination of the NHS and the extent to which GPs are used as proxies for patients. GPs function as providers as well as purchasers of care. This should be acknowledged and subject to open audit.

11.1 Health Improvement Programmes

The new Health Improvement Programmes should provide a planning framework that has been missing for some years and are broadly welcomed by ACHCEW.

Neither White Paper explicitly mentions CHCs in the context of Health Improvement Programmes. ACHCEW believes that, with their statutory duty to represent the interests in the health service of the public in their district, CHCs should play a significant role in this process. CHCs should be formally consulted on HIPs and involved at an early stage, and in an advisory capacity, in the development of HIPs.

11.2 Mergers of Health Authorities and the implications for CHCs

ACHCEW's position is that where health authorities merge, the presumption must be that the CHCs involved will not merge.

The first priority of the Secretary of State should be to ensure that the local communities involved are effectively represented. CHCs should only be merged where it is clear that the local communities would be more effectively represented by a merged CHC and where all the CHCs concerned agree that this is appropriate.

11.3 Primary Care

ACHCEW would expect Primary Care /Local Health Groups to hold public meetings and to consult locally about their plans.

In preparing legislation to establish Primary Care Groups the Government must ensure that Health Authorities have reserve powers to take over the management of Primary Care Groups should they fail.

CHCs should have a legal, explicit right to be consulted on all significant changes to commissioning intentions of the Primary Care/Local Health Groups and any other primary care providers such as dentists, opticians and pharmacists.

We would also expect Primary Care/Local Health Groups to operate openly and involve the local community in all decision making processes about the care to be commissioned. Special emphasis should be placed on ensuring that the views of "hard to reach groups" (such as black and ethnic minority communities and people with learning difficulties) are taken into account.

CHCs should be given speaking observer status on the Primary Care/Local Health Groups' governing bodies and have a right to enter and inspect all Group premises and any other sites where NHS primary care services are delivered.

Results of health authority audits or reviews of Primary Care/Local Health Groups should be made available to CHCs.

Primary Care/Local Health Groups should comply with the requirements laid down in the *Code of Practice on Openness in the NHS.*

Health authorities should be required to publish annual summaries of Primary Care/Local Health Group Performance.

Primary Care/Local Health Groups should set out in their published performance reports, the contact they have had with CHCs and the steps they have taken to involve patients in service planning, including measures such as the use of surveys and the establishment of Patient Participation Groups.

The performance reports should also specify the lessons which have been learned from patient complaints. Practice based complaints systems must be a mechanism for airing and addressing problems, not for smothering them.

11.4 NHS Trusts

ACHCEW welcomes the commitment to hold Trust Board meetings in public but we are concerned as to whether decisions by Trust Boards will really be made in public or whether the real decision making will take place "behind closed doors".

CHCs should have a right to participate (but not vote) at Trust Board meetings.

It should be a legal duty of Trusts to provide CHCs with such information about the planning and operation of health services in its area as the CHC may reasonably require in order to discharge its functions.

Trusts should be legally obliged to consult CHCs about substantial developments or substantial variations in service delivery.

Detailed information about the planning and operations of Trusts should be available to CHCs and full business plans should be published.

11.5 Specialist Services

There is no explicit mechanism for the involvement of CHCs although the English White Paper does state that "the NHS Executive will involve users and carers in its own work programme". ACHCEW would like to see a mechanism for directly involving patients in this process.

11.6 National Service Frameworks

National Service standards could be used to recommend that certain forms of treatment are not made available. ACHCEW would like reassurances that they will not be used to deny any effective forms of treatment to people who could benefit.

11.7 National Institute for Clinical Excellence (NICE)

As the statutory national body representing CHCs, ACHCEW would be ideally placed to represent patients' interests on NICE.

11.8 Commission for Health Improvement (CHI)

ACHCEW would like to see CHCs on this list of organisations that are able to invite the Commission for Health Improvement (CHI) to investigate.

11.9 Fairness and efficiency

Management costs are to be capped and bureaucracy reduced. Measures that improve the use of resources available to the NHS are to be welcomed.

However ACHCEW believes that NHS services are in huge demand and increased resources are needed if service provision, already badly stretched, is to be maintained.

ACHCEW is concerned that National Reference Costs could lead to a more explicit rationing that should only take place following public consultation.

11.10 Specific measures

ACHCEW welcomes the 24 hour nurse-led helpline as an innovative idea. ACHCEW would like clarification as to how the helpline will relate to the existing NHS Information-line; a reassurance that it will be a freephone number so as not to deter those on low incomes from using it; a reassurance that people living in Wales will have access to the service (the Welsh White Paper makes no mention of the service).

ACHCEW believes that patient confidentiality is of paramount importance and any new Information Technology led systems must satisfy stringent confidentiality requirements.

The English White Paper promises rapid referral to a specialist for anyone suspected of having cancer and the Welsh White Paper promises rapid referral for anyone with suspected breast cancer. Whilst cautiously welcoming these commitments to speed the referral to specialists, ACHCEW has reservations. We are concerned that it could lead to increased diagnosis of cancer without making it possible to treat these increased numbers. Patients could be fast tracked to a specialist only to find that there is then a waiting list for treatment. ACHCEW would like to see a commitment that this will not happen as it is a nonsense to fund rapid referral without providing the means to deliver the required treatment to those who have been referred.

11.11 Patients, CHCs and the new NHS

A national patient survey has the potential to be a useful exercise but it is important to have the survey properly validated by CHCs and other patients' organisations before it is used.

ACHCEW believe that patients' rights should be strengthened and in doing so make the NHS more accountable to the individual patient. We would like to see consideration of the rights contained in our *Patients' Agenda*.

The new White Papers present many opportunities for CHCs to demonstrate the unique contribution they are able to make in representing the views of patients and the local community. CHCs will need to be proactive in forging partnerships with the Primary Care Groups, NHS Trusts and health authorities, and it may be necessary to amend the statutory regulations to enable them to carry out their new roles effectively.

A national working group, which is led by CHCs and other user and carer representative organisations and with representation from the NHSE, should be established to develop national guidance / a national framework for public involvement and consultation. The guidance could pull together existing guidance, best practice and examples of public involvement which already exist.

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