

Statements of Support

"Patient Concern sees Patient Councils as a vital step on the long uphill road to a genuinely patient-centred, open and transparent healthcare service in this country."

Roger M. Goss Director - Patient Concern 28.3.02

"There is a definite need for a community lead at a local level. The inclusion of this [The Patients' Council amendment] in the Bill ... would greatly help to reduce the fragmentation of current proposals and improve the likely effectiveness of the plans".

Dr Simon Fradd, Chairman, Doctor Patient Partnerships.

"The Government has been truly determined to get rid of an effective local voice for patients in the form of Community Health Councils. It failed in its previous attempts in the face of opposition from backbenchers and in the Lords. This amendment [The Patients' Council] offers a compromise and an opportunity for patients to have an independent and powerful say in what's happening to their health services locally".

Simon Williams, Director of Policy, Patients' Association.

The Discussion Document [the governments 'Listening Exercise' on the new structures] does not present a range of options, instead it invites suggestions on a number of preferred models. This means there is no option for the reform of Community Health Councils, a move which was strongly supported by CVS in a recent piece of research.

CHCs present a known quantity to CVS and CVS have been almost universally involved in CHC elections in the past, as they represent an obvious 'gateway' to local voluntary and community sector groups keen to have lay representation.

A number of our members have also commented that the option for Patients Councils does not feature in this document. It was felt that such bodies would provide independent and integrated patient and public involvement in a way that the proposed structures do not.

The National Association of Councils for Voluntary Services October 2001

"The magnificent campaign from ACHCEW, supported by so many members of the public, eventually saw the government abandon its plans to abolish CHCs in the Health and Social Care Bill. But it may still be too soon to celebrate. Many pensioners rely on some aspect of the health service everyday of their lives and they understand the value of having an independent voice that can effectively represent the views of patients. Any attempt to downgrade or eliminate that role must therefore be resisted and we will do all we can to help keep CHCs alive and well."

Rodney Bickerstaffe, President National Pensioners Convention August 2001

"The NHS Retirement Fellowship, which represents about 16,000 former NHS staff, strongly urges the government to retain Community Health Councils. Our members feel that CHCs perform a valuable service: they act as the patients friend, they speak up for patients, they have experienced officers and dedicated members and above all, they are independent. Our national conference gave unanimous backing to a call for them to be retained."

Roger Stokoe, Director, NHS Retirement Fellowship, August 2001

"MSF believes that CHCs should be strengthened in their roles in order to retain an independent, patient focussed service to support local people in dealing with NHS trusts and to represent local views irrespective of political position."

Part of a motion carried by the MSF Annual Conference, June 2001

"Describing the abolition of Community Health Councils as giving more influence to patients seriously misrepresents a policy which could cost lives."

Dr Evan Harris MP, Liberal Democrat Shadow Health Secretary, commenting on the Queen's Speech 20/06/2001

"Patient empowerment: That this meeting of RCN Congress condemns the abolition of CHCs in England and calls for a national debate on effective patient empowerment."

Motion carried by Royal College of Nursing Annual Conference 23 May 2001, by a huge majority of 95.3% (382 votes) for, 3.2% (13) against, and 1.5% (6) abstentions

"We are very, very happy with this. This gives us more time to oppose the abolition of CHCs, which we see as the only independent body in the NHS which represents patients."

Patients Association May 11th 2001, on the news that the government had dropped the clauses relating to CHC abolition from the Health and Social Care Bill

MDF regrets the government's intention to abolish Community Health Councils and is concerned that the proposals for their replacement are not independent. We support the following principles agreed by Community Health Councils in England and Wales, Health Councils in Scotland, and Health and Social Services Councils in Northern Ireland, as essential elements of any new model for patient empowerment in the United Kingdom:

- **They must be** independent
- **They must have** statutory rights
- **They must be** integrated
- **They must be** service wide
- **They must be** people focussed
- **They must be** representative
- **They must be** transparent
- **They must have a** national body to co-ordinate and set standards

MDF asks the government to hold a public consultation on the proposed abolition, and on the appropriate model to modernise or replace them.

Michelle Rowett, Acting Chief Executive, The Manic Depression Fellowship, 14th February, 2001

The LGA supports the principle of local government responsibility for scrutiny of the health service and would wish to develop working models on how that scrutiny should operate in two tier areas. The LGA supports the principle of a robust and independent patient advocacy service which should be based on a reformed Community Health Council.

Local Government Association

"Pensioners as a group are one of the biggest users of the NHS. We have first hand experience of what modern-day healthcare really means and one of the most important issues remains the need for patients to have a strong voice representing their concerns. The requirement in a democratic society for an independent body, which will advocate the views of the wider community on all health matters, is therefore as vital today as ever. CHCs must not be abolished."

Jack Jones, President, National Pensioners Convention, 7th Feb, 2001

It should not be forgotten that Community Health Councils were established in 1974 as minor recompense for the reduction in community representation on NHS authorities. Since that date, by degrees that community representation has been reduced to vanishing point. The CHC remains the only statutory link between the community and health service management. On this account CHCs must be regarded as a fundamental safeguard for the community against the powerful and remote management structures of the NHS. Informed opinion laments the limitations imposed on CHCs, and it was hoped that the present government would honour its long term pledges by granting these bodies enhanced responsibilities.

The sudden about turn in Labour policy, its intention to abolish CHCs and replace them with a greatly inferior substitute, is not only damaging to the public interest but also in a variety of ways subversive to the main aspirations of Mr. Blair's government in the field of health care.

Dr Charles Webster, All Souls College Oxford

The Royal College of Obstetricians & Gynaecologists Consumers' Forum is concerned about the proposals in chapter 10 of the NHS Plan, which include the abolition of Community Health Councils (CHCs) and their partial replacement by a number of disparate bodies. The Forum shares concerns that have been raised about the fragmentation of CHC functions, the independence of the new bodies, and the absence of statutory rights...

CHCs have often provided independent support to women trying to make complaints about obstetricians and gynaecologists, and have helped them to pursue investigations and raise awareness. Examples are Northallerton and District CHC in the case of Dr Richard Neale, and South East Kent CHC in the case of Mr Rodney Ledward. However CHCs are also, through their day-to-day knowledge of local trusts, able to assess what progress is being made on particular issues, and what the best course is, both for the individual patient and for local patients in general...

The Forum therefore calls on the Government to conduct a full consultation on these issues, to ensure that any new arrangements do not lose the strengths of the Community Health Council system, and that they retain patient confidence.

Royal College of Obstetricians and Gynaecologists, 10th January 2001

There are a range of concerns about the proposals to replace CHCs with a new PALS system - not least that it is not clear on what basis the Government has decided CHCs should be abolished. Concerns about PALS centre on:

- whether PALS will be truly independent of the NHS;
- whether basing PALS in hospitals and other trusts will mean that they are truly accessible, especially for frail older people; and
- acknowledge that advocacy, liaison and facilitation are different skills. There may, as a result, be some conflict for the organisation in deciding which is its key role.

A key issue yet to be resolved is how the proposed PALS system will relate to the complaints system. The emphasis in the NHS Plan is for PALS to achieve resolution at an early, local stage. It is not yet clear whether they will also be able to fulfil the CHC role of actively supporting people as they take forward formal complaints - particularly if doing so is somehow seen as a failure of PALS to affect an earlier resolution.

Age Concern, Policy Unit, January 2001

We foresee a potential loss of the expertise that currently resides with the community health councils. In a recent survey by the DHN of councillor lay members of Primary Care Groups and Trusts, a significant number of councillors mentioned that an important source of training, information and development on health matters had come from community health councils. This may be because over half (50.3%) of the survey respondents had been CHC members. It is clear that councillors will continue to need a similar source of advice and expertise on the health service to fulfil the scrutiny role effectively. This support is unlikely to be available to them through the scrutiny support structures that are currently being developed in response to the Local Government Act.

We are opposed to the abolition of community health councils unless they are succeeded by independent area-based advocacy services, funded by central government, part of whose role would be to advise and support councillors in their health scrutiny function.

Extract from a parliamentary briefing prepared by the Democratic Health Network (DHN) at the Local Government Information Unit, January, 2001

"Community Health Councils have provided one of the very few opportunities for the ordinary citizens of Britain to make a direct, independent and useful voluntary contribution to the running of their NHS hospitals. The recent reorganisation of NHS primary care opens further possibilities for an extension of citizens' involvement in the planning and implementation of local NHS policies. The NHS Support Federation calls for a reassertion of the Government's stated determination to increase NHS accountability and democracy by abandoning the proposal to abolish CHCs. Instead, public representation should be greatly expanded by modifying CHCs to reflect the major new importance of Primary Care Groups and Trusts by replacing them with broader Unified Health Councils (UHCs) which bridge the Commissioner/Provider divide and express the public recognition of the importance of coordinated health services in which primary care and hospital staff collaborate in a single, well integrated health care structure.

"The Federation also very strongly supports the creation of NHS Public Training Courses, aimed at systematically and thoroughly preparing concerned citizens for more effective service on UHCs."

Professor Harry Keen CBE, NHS Support Federation, 12th January 2001

Clause 14 - Abolition of Community Health Councils in England

This clause abolishes Community Health Councils in England, and the Association of Community Health Councils for England and Wales.

Help the Aged is deeply concerned about the proposals to abolish Community Health Councils. We believe such a drastic move is premature, without a clear picture of what will replace them.

CHCs have provided an easily identifiable independent 'one stop shop' to patients with concerns about the NHS services that they have received, and have proved to be an effective local watchdog. Help the Aged accepts that the role and function of CHCs is in need of reform to strengthen their capacity to support patients and to broaden their scope to include primary care services. We do not believe that abolition without consultation is necessarily the way forward. We are particularly concerned that during a transitional period, patients will go unsupported.

The Bill proposes that the roles currently undertaken by CHCs will be divided up between Independent Local Advisory Forums, local authority Overview and Scrutiny Committees, Patients' Forums and the new PALs scheme. However, as the Bill stands, there is uncertainty about how those bodies will operate and fulfil their functions in practice, and how they will work together. Instead, the Bill proposes to answer these questions through regulation. Help the Aged is concerned that this will create a system which is not fully accountable and which has little or no statutory basis.

The fragmentation of CHC functions across several bodies is likely to lead to confusion and lack of clout in addressing the rights and representation of patients individually and collectively at an organisational level. Furthermore, there will certainly be a need for older people to be supported and recompensed in order to participate in the proposed new system at a practical level.

We suggest that there is still a need for an independent body to co-ordinate and support patient and community involvement at local level, and that it would be appropriate to give CHCs new roles and responsibilities to that effect rather than lose the expertise and good will that already exists.

Clause 15 - Power to abolish Community Health Councils in Wales

This clause gives the National Assembly for Wales powers to abolish Community Health Councils in Wales.

The National Assembly for Wales is currently undertaking a comprehensive consultation on the future of Community Health Councils.

Help the Aged is concerned that should the Assembly choose to retain CHCs while England abolishes them, patients in Wales and Scotland will continue to benefit from a clear statutory system of local accountability, while patients in England will be faced with a bewildering array of new structures and systems purporting to fill the void left by the abolition of CHCs.

Help the Aged Parliamentary Briefing Jan, 2001

Homeless People Set to Lose Advocates

The NHS plan proposes the abolition of all Community Health Councils by March 2002. Health Action for Homeless People has had a long association with Community Health Councils. They were instrumental in establishing the organisation and managing it for many years. London CHCs in particular have an understanding of the difficulties experienced by homeless people in accessing good health care and are effective in lobbying for improved access and for good quality specialist services.

Concerns about the proposed new system include the fact that there has been no consultation or evaluation of their role leading to the decision to abolish CHCs. CHCs have a history of taking up issues for the dis-empowered within the community: refugees, homeless people, non-English speakers. The new system will not replace this invaluable role. In relation to individual complaints and the PALS, it is hard to imagine how they will maintain independence and be advocates for patients when they are situated in the heart of a hospital. The independent advisory forum sounds in principle like a good idea: but how representative will they be, and will they have the interests of all sections of the community and the principles of equity and non-discrimination at heart? The local authority scrutiny panel is intended to bring the NHS under more democratic control, but will councillors have the capacity to cope with the increased workload? Will they be involved enough to understand the detailed implications of decisions?

Health Action for Homeless People, Outcry Jan, 2001

The National Childbirth Trust would like to express its concerns about the government proposal for the abolition of CHCs.

For the last twenty six years CHCs have done tremendous work and have often been a major voice for patient empowerment. The NCT sees Government proposals for the abolition of CHCs as a threat to the cause of user protection, representation and involvement. NCT has particular concerns about the loss of :

- Independence
- Political impartiality
- Informed overview
- Legal Powers

CHCs are effective partly because of their independence from local health care bodies. If the proposed reforms go ahead, independence will be lost as newly proposed bodies, like the Patient Advocacy Liaison Services (PALS), will be managed by the NHS trusts. NCT also has concerns about fragmentation of knowledge and advocacy, if responsibilities are divided between five different agencies.

A major concern is the loss of legal power to be consulted upon the reconfiguration of maternity services. Currently CHCs must be consulted on any planned closure of a maternity unit and have the right to refer cases to the Secretary of State for the ultimate decision. It is proposed that the right to refer would pass to the local authority scrutiny committee. We are concerned that these local authority scrutiny committees may be influenced by party politics and subject to bias. We are also concerned that the scrutiny committee would have no power to refer to the Secretary of State but would instead refer hospital closure to an unelected and unaccountable national configuration panel. Furthermore, no clear criteria have been set as to which cases would be eligible and how they would be referred.

Given the above reservations, the NCT calls upon the Government to either review its proposal to abolish CHCs or to retain independence, political impartiality, overview and legal power within any new structures.

The NCT urges the Government to carry out a public consultation on its proposals for 'reforming' patient representation.

Mary Newburn, Head of Policy Research. NCT

We have two major reservations [about the National Plan]. The first is that the essential tradition of advocacy in the field of learning disability is, apart from self- advocacy, one of independent advocacy. Independent advocacy seems to be missing in the new arrangements. The second is that the logic of abandoning Community Health Councils is not apparent. Whatever the shortcomings of some of them, the CHC system is well established, and it seems grossly irresponsible to abolish it with no explanation and no adequate substitute.

E.B. McGinnis MENCAP

"We are deeply concerned that the Government is prepared to take the radical step of abolishing CHCs without first having a period of public consultation. As solicitors we believe that the abolition of CHCs would be bad for the patients we represent and result in greater litigation and more cost to the taxpayer and patients alike.

"The Government has often said that it is keen to 'enhance patient empowerment' but abolishing the CHCs will reduce patients rights and incur greater costs. If there is going to be a change to the vital role performed by CHCs and even a possibility that they may be abolished then, in the interests of patients, there must be proper consultation about this."

Carolyn Kirby, Deputy Vice President of the Law Society and Chair of the Mental Health and Disability Committee 6th November, 2000

In a letter sent to the Secretary of State for Health, the Rt Hon Mr Alan Milburn MP, the BMA expresses its concern over their [CHCs] abolition and calls for their function to be retained. Chairman of the BMA, Dr Ian Bogle said:

"Many doctors work very closely with the local patient representative groups and have benefited from their collaboration. Removing these powers would seriously threaten patient advocacy. The new arrangements must be independent of NHS structures and carry with them the statutory powers to preserve advocacy, scrutiny and inspection. It is vital that they strengthen, not weaken, the roles currently held locally."

Quote from BMA Press Release Thursday 9 November 2000

"The Department of Health has failed to give any rational explanation for their proposal to abolish community health councils (CHCs). We need to know why they are being abolished.

"There is no way that the alternative proposals can replace the work that the best CHCs have been doing, particularly in relation to patients' complaints. We are deeply concerned that the statutory rights that enable CHCs to act on behalf of patients and the public will be lost if the proposals are implemented. CHCs must not be abolished until the proposed new bodies have proved themselves to be independent of the NHS and effective representatives of patients and the public."

Arnold Simanowitz – Chief Executive AVMA (Action for Victims of Medical Accidents)

The Assembly notes that the governments current NHS Plan proposes the abolition of the CHCs and the division of their functions between four new local bodies: the patient advisory and liaison service, the patients forum, an advisory citizens panel and the all party scrutiny committee of the local authority. The Assembly expresses its concern that these proposed new bodies may lack the independence which enables the CHC to speak up frankly, effectively and constructively for the patients' interests. We ask the Chair of the Assembly to write to the Minister of Health expressing this concern.

Greater London Assembly, motion passed unanimously 18 October 2000

"Age Concern believes that the Government has missed an opportunity to bring in a strategic approach to advocacy across all services. There are proposals for new hospital-based 'patient advocacy liaison services' (PALS), and the abolition of community health councils (CHCs), which were and were perceived to be independent. CHCs have had a wider role than solely representing individuals, and their abolition is a considerable cause for concern. "

Gordon Lishman - Director-General of Age Concern England British Journal of Community Nursing 200 vol 5 No 9, September 2000

"This Association regrets the Government's intention to abolish the Community Health Councils (CHCs) and calls upon the Government to ensure that consumers of health services will enjoy access to independent advocacy and consumer representation."

Motion passed by the National Association of Citizens' Advice Bureaux at annual conference 2000

"We firmly believe that there must be an independent voice speaking for the community in regards to local health care provision and health policy. Community Health Councils clearly have a vital role to play in this."

Stuart Etherington, Chief Executive NCVO (29th November 2000)

"First, access to independent, expert advice to complainants is essential both for public confidence and to ensure that poor practice is identified. It is important that patients feels supported in making sound complaints and that they receive full and impartial advice about the range of options including, where appropriate, complaints to the GMC and litigation.

"Secondly, there is a strong case for a national network of organisations to promote the public interest in health care...ACHCEW has been effective in raising important points of concerns about the standard of care provided by the NHS. Other national organisations may not have the same independence of central government or, therefore, contribute in the same way to the accountability of the NHS".

"I would like both an independent advice service and a national body representing the public interest to cover all health care and not to be restricted to NHS patients."

Sir Donald Irvine CBE – President, General Medical Council

"Labour's strong preference is for highly centralised organizations, which owe their loyalty to Ministers, and are thus to all intents and purposes gagged. We have seen this again with the bodies which they have created to replace CHCs.

"The Conservatives oppose the abolition of CHCs. We would not have abolished them, but instead built on their strengths in consultation with the public."

Liam Fox, Shadow Secretary of State for Health

"But although the National Plan paid lip service to the idea that accountability had to be improved and decision-making delegated, Health Secretary Alan Milburn has proved the great centraliser and eliminator of checks and balances. He used his prerogative powers summarily to abolish the patients' watchdog, the Community Health Councils, replacing sustained local scrutiny with a flimsy system of twice-yearly appearances by NHS trust chief executives before local authority committees. Both could have co-existed, but that would have implied too great a challenge to executive authority. "

Will Hutton, The Observer Sunday 29th October, 2000

"We are truly appalled with the Government's proposal to do away with Community Health Councils. CHCs have, in the past, produced some superb reports and have a wealth of experience and we are dismayed at even the idea of their removal."

Beverley A Lawrence Beech – Honorary Chair, AIMS (Association for the Improvements in the Maternity Services)

Conference pays tribute to the work, over 26 years, of Community Health Councils, both the permanent staff and voluntary members.

"Conference believes that CHCs perform an important scrutiny role and form a vital focal point within the community for monitoring and commenting on the NHS, providing help and information for individuals, and defending and promoting the interests not just of patients, but also of carers and NHS staff.

"Whilst accepting that there is scope for reform, Conference condemns the sudden decision to abolish CHCs which was announced, without prior specific consultation, in the Government's 'NHS Plan', and considers that the planned replacements are fragmented and ill-conceived.

"Conference therefore calls upon the Government to abandon its declared intention to abolish CHCs and instead to discuss and consult on how their role can best be reformed, improved and strengthened."

Liberal Democrat conference, Bournemouth. Motion passed conference 2000

"PATIENT CONCERN regrets the government's decision to abolish CHCs. This has been taken without consultation and goes against the recommendations of their own Select Committee.

"Some CHCs were excellent - others were inadequate for their task, mainly because they lacked proper resources and a clear mandate on their role as patient advocates. Properly reorganised, they could have been the strong national voice that patients need. Instead all the valuable experience and solid framework built up over the years is to be swept away. This cannot be in the interest of patients.

"The proposal to set up a patient forum in every Trust is a step forward - but only if these are in addition to an independent, outside body with some form of national co-ordination. The National Plan pays lip service to the idea of strengthening the influence of patient views. In

reality, the new arrangements are likely to leave the patient voice fragmented, localised and easy to ignore.

"When one of the directors of PATIENT CONCERN challenged Alan Milburn on the issue of CHCs when the National Plan was launched, he dismissed them as an 'old idea'. This suggests that the decision is entirely political, with respected organisations being swept away in favour of the 'eye-catching new initiatives' sought by this government.

"This is no way to create a patient-centred service."

Joyce Robins – Director, Patient Concern

"This Conference calls upon HM Government to urgently withdraw its proposal (contained in the NHS Plan) to abolish Community Health Councils (CHCs) and instead build upon the achievements of the CHCs over the past 26 years in pioneering patient empowerment, improving patients rights, and developing continuous scrutiny of the policies and operational plans of local health authorities, NHS Trusts, and Primary Care Groups and Trusts which affect patients and the public; providing professional support to patients who wish to make a formal complaint and professional advocacy services to NHS patients of both primary, acute, and community care both public and independent, as well as providing £7.9 million worth of voluntary labour from Members of CHCs who are appointed through the voluntary sector and democratically elected local government.

"The Government are requested, by this resolution, to introduce the Patient Advocacy and Liaison Services (PALS) as an extension of the services provided by the CHCs which would ensure the vital independence from local NHS management required and needed by patients to give them confidence in the advice and help they receive; ensure the continuance of vigorous local scrutiny, as well as being better value for money."

Motion passed at the Co-operative Party conference, 2000

The College of Health regrets the lack of discussion with public and patient groups prior to the decision to abolish Community Health Councils announced in the NHS Plan. CHCs have important statutory rights and duties to represent the views and needs of their local populations and to be consulted on proposed changes in the provision of care by health authorities and trusts. We are concerned that under the new arrangements proposed, these important statutory rights should be strengthened and not weakened to the detriment of patient and public empowerment.

While welcoming the introduction of Patient Advocacy and Liaison Services (PALS) to trusts and acknowledging the important role they should have in helping patients sort out problems before they become complaints, we have strong reservations about the extent to which they will be seen as truly independent by patients who have a complaint about the trust, if the trusts employ and direct the work of the advocates. We are also concerned that PALS based in hospitals may be badly placed to help the majority of patients whose problems are to do with community or primary health care or with failure to access the services they need or relate to lack of co-ordination between primary and secondary care and with social services.

The College of Health's other main concern is that we risk fragmentation at local level and, importantly, the loss of a mechanism for monitoring and identifying national trends and patterns in both good and bad practice through the sharing of local knowledge and experience.

Marianne Rigge, Director Graham Lister, Chair College of Health 15 November 2000

The Doctor Patient Partnership strongly support the continued need for independent patient advocacy with statutory power. It is crucial that the role of CHCs to advocate, scrutinise and inspect be continued both on a local and national level. The CHCs play a key role in providing these support mechanisms for both primary and secondary care. It is vital that this role in primary care is not lost. Plans to replace CHCs focus on secondary care even though patients need the help of a patient advocate just as much in primary care.

The DPP would like to offer our continued support to ACHCEW.

Dr Simon Fradd, Chairman of Doctor Patient Partnership

We are not convinced that the proposals to abolish Community Health Councils in England and establish new organisations that have been announced will improve on the current arrangements. Any new organisational arrangements to replace CHCs must ensure effective representation for each local community and satisfy these principles:

- Free at the point of use
- Perceptibly independent of NHS providers
- Accessible - geographically and culturally
- An integrated service
- With Statutory rights to information - without any protection in respect of commercial confidentiality of any organisation proposing to undertake contracts with the NHS, - to access to any premises from which care or treatment is delivered, and to be consulted about proposals for substantial changes in services
- An evolutionary improvement on existing systems
- Service wide, not confined to services provided by any one organisation
- Enabling for individuals
- People focussed
- Representative
- Locally responsive
- Transparent, public, and accountable, particularly in the appointment process
- Properly resourced, trained, and managed to quality standards
- With a national body capable of drawing together experience across the whole country and ensuring consistent standards ...

The better CHCs have built up considerable expertise in their local health economies. If these new institutions are to operate effectively some mechanism must be found which will preserve and develop this expertise.

We are concerned that the process by which changes in democracy and accountability arrangements is being made is not in the least transparent. Ministers have asserted that discussions are continuing and wide ranging. We have reason to doubt that these discussions are open to all those who might have something to contribute. We would certainly be keen to enter into dialogue with ministers about how patients can most effectively be empowered.

Extract from Socialist Health Association Press Release 9/12/00

Martin Rathfelder, Development Director