



Association of Community Health Councils for England and Wales
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The Golden Age of Patient and Public Involvement



ACHCEW is committed to maintaining the highest quality and quantity of work for CHCs, despite imminent abolition and redundancy which has hung over the organisation for two years.

It is a credit to staff who have left over the past year and those who remain that ACHCEW's excellent services and work output has continued undiminished to the very end.

Human Rights

Our new report, 'Human Rights in the Health Service' identified a range of areas in which the NHS could be vulnerable to legal action under human rights legislation. Potential areas of legal challenge to the NHS include treatment of the elderly, patient confidentiality and the treatment of people with mental health problems.

Parliamentary Affairs

ACHCEW's parliamentary work has proven extremely successful. In addition to briefing leading members of the House and party spokespeople on issues around patient and public involvement the organisation has made a significant impact across a range of policy areas. This includes presenting evidence to the Health Select Committee on the issue of Foundation Hospitals.

Tax on illness

Questions from CHCs about the legality of charges for some NHS Services led to the production of a briefing on the subject and subsequently to the campaign to abolish prescription charges. This work, triggered by CHCs, has influenced bodies like the BMA, who have come out in support of the campaign. Although the UK government is still not convinced, it appears that the Welsh Assembly may be the first to move towards abolishing prescription charges.

OSC Training Pack

ACHCEW's training team has put together a pack that will be at the core of preparing members of Overview and Scrutiny Committees (OSC) for their new role in monitoring the NHS. The project was commissioned by the Department of Health. OSC members will benefit for many years to come from the lessons learned by CHCs.

Media

ACHCEW has enjoyed an extremely high media profile over the last year. We have established and maintained our status as the leading commentator on the new patient and public involvement structures.

Our articles and messages have appeared across a wide range of media including, national press, specialist health press, radio and television.

Data Protection Act

The Data Protection Act briefing produced by ACHCEW's legal team, drew attention both to problems with the Act from a patient's point of view and highlighted how it could be used by patients advocates.

In the words of one reviewer the briefing made 'the impenetrable accessible'.

Administration

Despite the reduction in numbers, the administrative team have continued to keep the organisation functioning. During the past year, 6 meetings of the Standing Committee and 8 meetings of the Honorary Officers were arranged. In addition the, highly successful final Annual General Meeting was organised.

FROM THE CHAIR AND DIRECTOR

Celebrating the Golden Age

Thirty years after the NHS was born the Health Minister, Barbara Castle published a document called Democracy in the NHS in which she wrote:

'The task now is to develop the CHCs into a powerful forum where consumer views can influence the NHS and where local participation in the running of the NHS can become a reality.' Barbara Castle 1974



Alan Hartley

Malcolm Alexander

Photo: Bill Marks

Community Health Councils across the UK took on the challenge, developed powerful local bodies, extended their influence to every part of the NHS, developed patient complaint and advocacy services, campaigned, argued, negotiated, became partners in the development of new services and stopped the irresponsible closing of hospitals, wards and beds. They sat in stuffy NHS boardrooms across the country, arguing for services responsive to local needs, an end to waiting lists and a change to the hierarchical medical model that dominated the NHS.

Their successes were phenomenal. CHC members became a

force to be reckoned with; their searching reports on health services a challenge to the elites that ruled local health services, their inspections treated with concern, respect and sometimes panic as attempts were made to conceal poor standards and their interventions at Health Authority Board meetings (and sometimes in the courts) as a powerful challenge to health policy made on the hoof or sometimes as a response to the annual financial crisis.

CHCs were characterised by their proud independence, the sheer intensity of work that the dedicated members and staff put in to improve the quality of the local NHS and the deeply moving relationships developed with local communities. Through campaigning for better services, supporting user groups, working with the voluntary sector and supporting people with complaints, CHCs became hubs of activity for improvement of local services. Patient and public involvement, which in 1974 had seemed a mere aspiration, became a whirlwind of activity and achievement.

As CHCs developed their self-confidence they turned from being reactive to proactive. From being merely defensive – 'save our services' - organisations they turned their attention to service development, stimulating communities to work in partnerships to create new health services. Complaints work became transformed as case workers developed into powerful advocates for patients and families who had suffered at the hands of poorly controlled and monitored health services. Governance of the NHS became a key theme, as CHCs developed the expertise to identify key performance issues and the skills to transform local services for the benefit of local people. Monitoring of health services was an activity that preoccupied CHC members - continuous activity that often brought immediate benefits for patients. This developed into co-ordinated activities like Casualty Watch which created powerful networks capable of challenging performance and NHS policy at the highest level – the power of patients and the public had come of age.

Strong foundations have been laid for new and dynamic developments in patient and public involvement, which will be led by the Commission for Patient and Public Involvement and almost 600 Patients' Forums across England. A careful process of transition is essential to ensure that the great potential the CPPIH can offer for the future of patient and public involvement is not squandered by forgetting to learn from our brilliant past.



Malcolm Alexander DIRECTOR

Photo: Crispin Hughes photo fusion

The new Commission for Patient and Public Involvement (CPPIH), which was established on January 1st 2003 and which is accountable to the Secretary of State, has only sketchy plans to fill the monitoring gap. Neither the Secretary of State nor the CPPIH know when Patients' Forums will have the capacity to restart the process of monitoring and engaging with patients. Consequently, flagship projects like Casualty Watch will simply die.

CHC members have no idea if they will be invited to have a role in the new system, despite their wealth of experience and knowledge about the NHS. Many have put in years of voluntary service to their communities, but instead of being valued for their contribution and impact on the

Oh No Minister!

The transition between CHCs and Patients' Forums will go down in health service history as an era of chaos and confusion. Where there had been commitment and harmony, Alan Milburn's stewardship of the development of patient and public involvement (PPI) created despair and antagonism.

Transition has been marked by an absence of process and planning and insufficient concern for either the patients or the public who are clients of CHCs. Neither has there been much concern for the members and staff who have been the bedrock of

PPI in the NHS. They are the reason for the great success of the public involvement movement, which has made such phenomenal gains for patients over the past 28 years. They were the people who created this great movement in England and Wales despite meagre resources and the indifference of the Department of Health.

On December 1st 2003, community monitoring of the NHS by CHCs across England will come to an end and left in abeyance until Patients' Forums become fully operational in 2004. The Welsh Assembly on the other hand decided to retain and support CHCs and work closely with them to ensure the continuing development of PPI in health and to enhance their impact on the Welsh health service.

NHS, members feel they are about to be discarded.

The poorly planned abolition of CHCs has discredited the Government and disempowered patients and carers. A vacuum has been left in the NHS where once there was active engagement, continuous monitoring and creative partnerships between communities and their local health services.

The abolition of CHCs was once trumpeted by the Government as a way of giving patients more power, putting them in the centre of decision making and transforming health care. But their drive for change at any cost outstripped the Government's abilities when it came to planning the new system.

A ferocious two year campaign by CHCs, ACHCEW and voluntary organisations across the land, forced the Government to drop their original plans and instead to produce a system that seemed workable. Despite this the Secretary of State has allowed the CPPIH to start the process of setting up the new 571 Patients' Forums in England through a highly complex and disorientating process of tendering through the voluntary sector. Ironically a system which was criticised for patchiness is to be replaced by a system in which patchiness is inevitable.

And now the spectre of Foundation Trusts and Foundation PCTs is on the horizon. Not content with destroying English CHCs and ACHCEW, Alan Milburn is now intent on developing a new system of Foundation Trusts, which will have no Patients' Forums. Alan Milburn has signed the death warrant for the new PPI system, before the new Patients' Forums have even been born.

We share with the Government the ideal of putting patients at the heart of the NHS – what a shame they had to throw into reverse 28 years of highly effective community involvement in the NHS, for want of a rational and consistent policy that would give patients' the power to make that heart beat with new life.



Cartoon by Tim Sanders

Building the Foundations for the Future

Getting involved in shaping and developing the new patient and public involvement structure is now the greatest priority for CHC members and staff and communities across England.

The new system of patient and public involvement is complex and it would be tragic if the complexities of the new system dissuaded patients, carers and community activists from getting involved. The success of the new system depends upon the highest possible level of patient and public involvement both locally and nationally in the CPPIH itself.

Highly active community networks, that have been developed by CHCs and the voluntary sector across the country, need to remain intact and able to influence the membership and development of local Patients' Forums. This will be difficult in the absence of local CHCs to provide the resources and support necessary, but it is essential that volunteers who have been active in monitoring and developing the NHS, keep active and in contact and provide the support that will be essential to build the new PPI system. The new Section 11 duties on all NHS bodies to involve the public will provide important opportunities for volunteers. National bodies like the Patients' Forum, CHI (CHAI), NICE, the Patients' Safety Agency and the GMC provide other ways of keeping in touch with developments in health care and health policy.

The worst case scenario would be for despair caused by the way the abolition has been managed to turn people away from working with the new Forums and the CPPIH. Only local ownership of the new Forums by active communities and active engagement with the CPPIH will ensure that the great legacy of CHCs – the empowerment of patients and the development of real power bases in the NHS will help to create even more effective ways of ensuring that the NHS meets local needs and serves local people.

ACHCEW warmly welcome the Commission for Patient and Public Involvement and is certain that the Commissioners will build a great new patient and public involvement system on the strong and deep foundations carefully laid by CHCs over the past 28 years.

“Thank you more than words can adequately express for your help in sorting out my communication problem in my complaints appeal. The time and the care you have given to my case has been far more than I could have hoped.

It was so kind of you to deliver the letter too. I picked it up when I got home last night.”

Complainant anonymous

“CHC support was invaluable when we had a meeting with senior members of hospital personnel. I am sorry that this service is to be discontinued, without it some might feel unable to push forward a complaint or problem.”

Complainant anonymous

“My mother found it most helpful to be able to voice her concerns to someone who understood the NHS system and would also listen to her anxieties.”

Complainant anonymous

“I think that this service is of great value and it would be a great loss if it was discontinued. At a time of sadness for me the service gave me focus and strength to plan my complaint and the information I received was of great help to me.”

Complainant anonymous

“Without the CHCs I would not have known where to turn. They have been a tremendous source of help and support at time when no one else was remotely interested... Without their help I would have had no one to help me: no solicitors firms, no charity, no one would or could help me.”

Mrs Dorothy Forbes complainant
(Wandsworth/Balham)

“Thank you for sticking by me throughout this ordeal and for being outspoken in my support. Thank you for being a tiny light in a sea of neglect.”

David Brown (Southwark)

Who's Who at ACHCEW

| | |
|-------------------|------------------------------|
| Malcolm Alexander | Director |
| Peter Walsh | Director until December 2002 |
| Allison Anthony | Training Organiser |
| Ray Appleby | Policy Officer |
| Murray Benham | Communications Manager |
| Vera Beswick | Administrative Assistant |
| Angeline Burke | Senior Policy Officer |
| Marion Chester | Legal Officer |
| Chye Choo | Chief Administrative Officer |
| Sheila Dollery | Administrative Assistant |
| Maggie Flynn | Administrative Assistant |
| Diane Jones | PA to Director |
| Estelle Kiss | Information Assistant |
| Frances Presley | Policy Officer |
| Liz Rickarby | Training Organiser |
| Anya Stern | Legal Assistant |

Standing Committee

Congratulations and thanks are owed to Standing Committee members, all of whom have been a source of outstanding strength to the organisation throughout a difficult year.

A debt of gratitude is also owed to the Associations Honorary Officers, who have given so freely of their time, experience and judgement. Without them the organisation would not have been able to achieve all it has over the past year.

Honorary Officers

| | |
|----------------|----------------------|
| Alan Hartley | (Chair) |
| Sally Brearley | (Vice-Chair) |
| Donald Roy | (Vice-Chair) |
| Graham Girvan | (Honorary Treasurer) |

North & Yorkshire

Valerie Bryden
Trevor Gauntlett
Cllr Ian Mason

South East

Gordon Peake
Frank Rust
Frances Johnson

Trent

Barry Fippard
David Walsh
Susan O'Donnell

South West

Mark Woodcock
Alice Clarke

Eastern

Keith Jackson
John Biggs
Tony Tester

West Midlands

David Spilsbury
Pauline Davis
David Mattocks

London

Judith Blakeman
Bill Marks
Celia Davies

North West

Cath Arnold
John Seddon

Wales

Tommy Morgan
Jane Jeffs

Bill Coltham Society of CHC Staff Observer

Contact ACHCEW

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