

HSCNEWS *international*

INTERNATIONAL NEWS for HEALTH and SOCIAL CAMPAIGNERS

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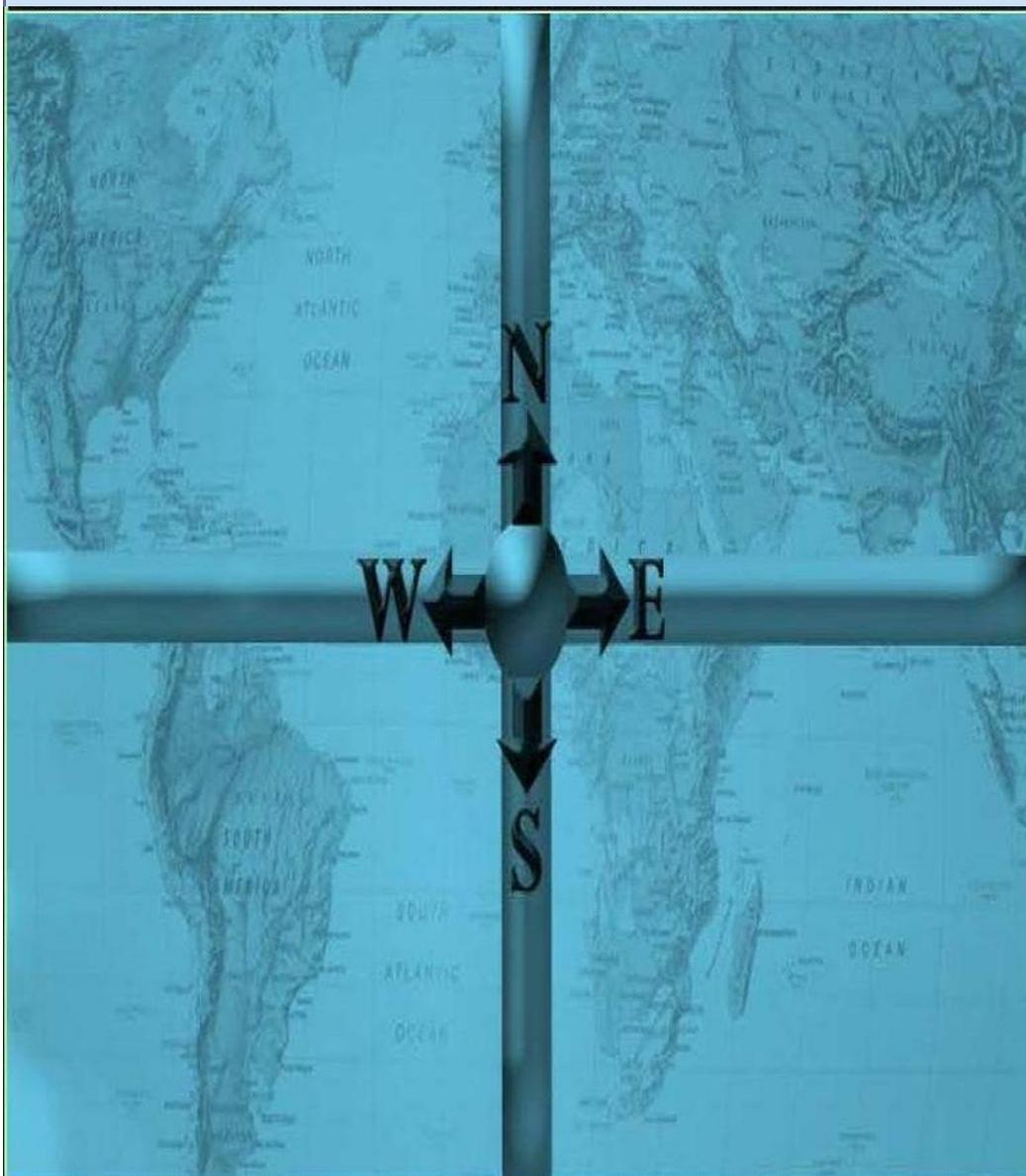
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**Health and Social
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News international

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— Marian Nicholson, Director, Herpes Virus Association [UK]

— Anne Greenwood, Managing Director, Current Controlled Trials Ltd [UK]

European News

This issue of *HSCNews international* focuses on:

The UK National Health Service, and its user-led experiment in health reform that may never be

and

A mini-poll that reveals European variations on the public availability of prescription medicines information

The end of the world's most ambitious user-led experiment in healthcare restructuring?

During seven years in office in the UK, the Labour Party has continued to emphasise its plans to turn the National Health Service (NHS) into a patient-focused organisation. The legislative and administrative changes initiated have been heralded as one of the ambitious experiments in user-led healthcare reform anywhere in the world. But on July 22nd 2004, the Government made a 'u-turn' and announced the abolition of the newly-launched Commission for Patient and Public Involvement in Health (CPPIH), a cornerstone of its grand idea. HSCNews international discusses the latest turn of events through the voices of individuals working on behalf of patients and the public.

A patient-centred Reform Plan

The UK's ruling Labour Party continually reiterates its desire to make healthcare more patient focused

When the Labour Party came to power in the UK in May 1997, the new Government pledged to improve radically public health services. In keeping with this pledge, the National Health Services (NHS) Reform Plan for England, unveiled in July 2000, called for a patient-focused healthcare system. The Plan was probably the first occasion in which any country had produced a blueprint placing patients at the heart of a process of healthcare restructuring. The framework and principles by which a new patient-oriented culture would be created at every level of the NHS were further outlined in a Government programme, *Shifting the Balance of Power: Securing the Service*, published in September 2001 [<http://www.publications.doh.gov.uk/shiftingthebalance/hrguidance/hrguidance.pdf>]. In June 2004, the vision was reiterated for the next five years in a forward-looking document, *The NHS Improvement Plan: Putting People at the Heart of Public Services*, which set out the NHS programme for 2004-2008.

The plan was for healthcare to be run locally, with patient input

In a nutshell, the grand vision originally proposed by the then new Labour administration was a decentralised NHS in which the role of central government would be downgraded to three functions: setting national standards, overseeing regulation, and funding the NHS. Healthcare services would be managed and supervised locally. Patients and the public would have a greater say in how their NHS should be run. The Government's top two

The NHS Reform Plan was the first occasion any country placed patients at the heart of the healthcare system

**The NHS
Plan of 2000
has been
beefed up by
the arrival of
new bodies,
including
PALS ...**

... ICAS ...

... OSCs ...

**... and the
Commission
for Patient
and Public
Involvement
in Health**

priorities were abolishing inequities in access to healthcare services, and creating an NHS that reflected the needs of diverse local populations.

2000-2004: the NHS Plan takes on substance

As the NHS Plan unfolded, a number of new administrative bodies were created and high-level appointments announced. Some of the new entities were situated centrally, within the Department of Health (DoH). Others were positioned at a local level in healthcare provision. Key events were as follows:

- All Trusts had established a **Patient Advice and Liaison Services (PALS)** from April 2002. The PALS provide resources to patients, their relatives and carers. They help patients resolve concerns with NHS services quickly. The PALS also act as general advisors, enabling patients to utilise the NHS to their own best advantage.
- Harry Cayton, formerly chief executive of the [Alzheimer's Society](#), was appointed **National Director for Patients and the Public** in May 2002. His brief was to advise ministers on how best to build a patient-centred NHS.
- First piloted in September 2002, the **Independent Complaints Advocacy Service (ICAS)** became available nationwide by the end of 2003. The ICAS provides a free, local, confidential service, allowing patients to make formal complaints about their experiences within the NHS.
- New legislation known as the 'Local Authority Overview and Scrutiny Committees (OSC)s Health Scrutiny Functions Regulations 2002' came into force on January 1st 2003. **Overview and Scrutiny Committees (OSCs)** have legal rights to intervene on healthcare matters within their own local area. The Committees marked the first moment in which democratically-elected local government was given the authority to tackle NHS problems.
- Established in January 2003, but not officially launched until February 2004, the [Commission for Patient and Public Involvement in Health \(CPPIH\)](#) represented the final piece in the jigsaw that was the Government's plan to create a patient-focused NHS. Financed by the DoH, the CPPIH was allocated a budget of £36million [53 million Euros, US\$69 million] in its

Bodies and processes within the English NHS: some definitions

Trusts: financially autonomous organisations which may run hospitals (Hospital Trusts) or primary care services within a given area (Primary Care Trusts, or PCTs), or other types of services, including mental health. Trusts are separate from local government.

PCTs: manage GP practices and frontline community health services.

The Healthcare Commission, launched on April 1st 2004, replaced inspectorates for private and NHS care. The new independent healthcare inspectorate (full name Commission for Healthcare Audit and Inspection) is charged with inspecting health services, reviewing their performance and publishing the results. The Commission will also work with other bodies to reduce the bureaucracy of regulation.

first year. The organisation acts as an umbrella group, providing administrative support to 572 **Patient and Public Involvement Forums (PPIFs)**, which are based in each health Trust in England. Manned by local volunteers who might be patients or members of the public interested in health issues, the PPIFs provide input from patients on the running of local NHS services (concentrating, in particular, on how these services can be improved).

The CPPIH's Forums are intended to be a bridge between the NHS and local people

The hope and idea was that popular opinion would be passed on to the CPPIH, which would direct its findings to the Government's Secretary of State for Health. Ideally, the PPIFs would form a bridge between the NHS and the local community. Members of the PPIFs have legal powers to pass on recommendations to OSCs. At the CPPIH launch, Laura McMurtrie, chief executive of the organisation, stated: *"the new structures give ordinary people the opportunity to help drive change. They put the patient and the public at the heart of our healthcare system. You will be able to make decision-making more local, and ensure that local NHS providers respond to the needs of the local community."* The intention was that the CPPIH should eventually take over the running of the Independent Complaints Advocacy Service (ICAS).

The CPPIH and the PPIFs: contentious and ambitious

A May 2004 Socialist Health Association meeting discusses the CPPIH

The Commission for Patient and Public Involvement in Health (CPPIH) and the Patient and Public Involvement Forums (PPIFs) were perhaps the most ambitious and contentious part of the patient-centred NHS Reform Plan. The reasons why were explained at a meeting entitled 'New Directions in Patient and Public Involvement', held by the [Socialist Health Association \(SHA\)](#) on May 15th 2004 in Birmingham, England.

Speakers at the SHA meeting included:

- Lord Philip Hunt, Chair of the National Patient Safety Agency (NPSA), an authority created in July 2001 to coordinate

Some Web Addresses

Commission for Patient and Public Involvement in Health (CPPIH)

<http://www.cppih.org/>

Independent Complaints Advocacy Service (ICAS)

<http://www.cppih.org/icas.html>

National Director for Patients and the Public (Harry Cayton)

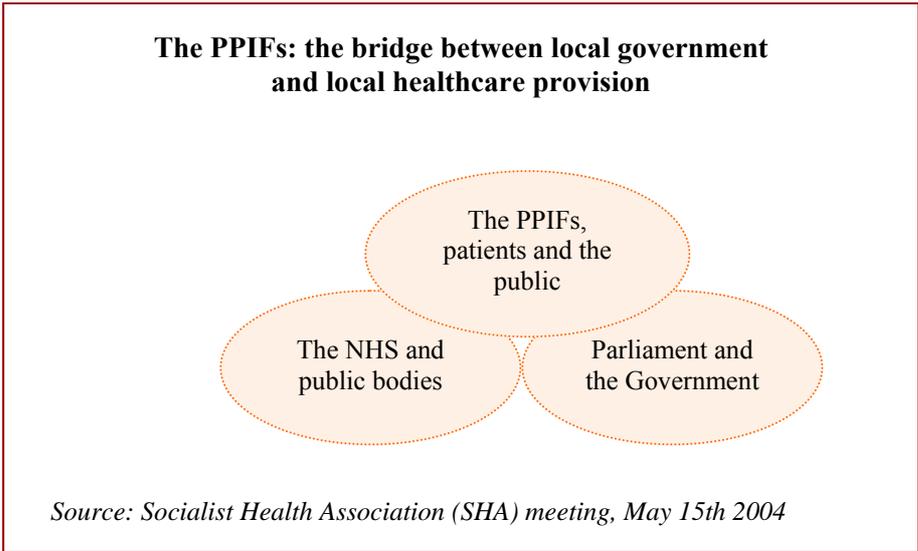
http://www.dh.gov.uk/AboutUs/MinistersAndDepartmentLeaders/DepartmentLeaders/NationalClinicalDirectors/NationalClinicalDirectorsBiography/fs/en?CONTENT_ID=4076986&chk=L7ForR

Patient Advice and Liaison Services (PALS)

<http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/PatientAdviceAndLiaisonServices/fs/en>

Patient and Public Involvement Forums (PPIFs)

http://www.cppih.org/ppi_new.htm

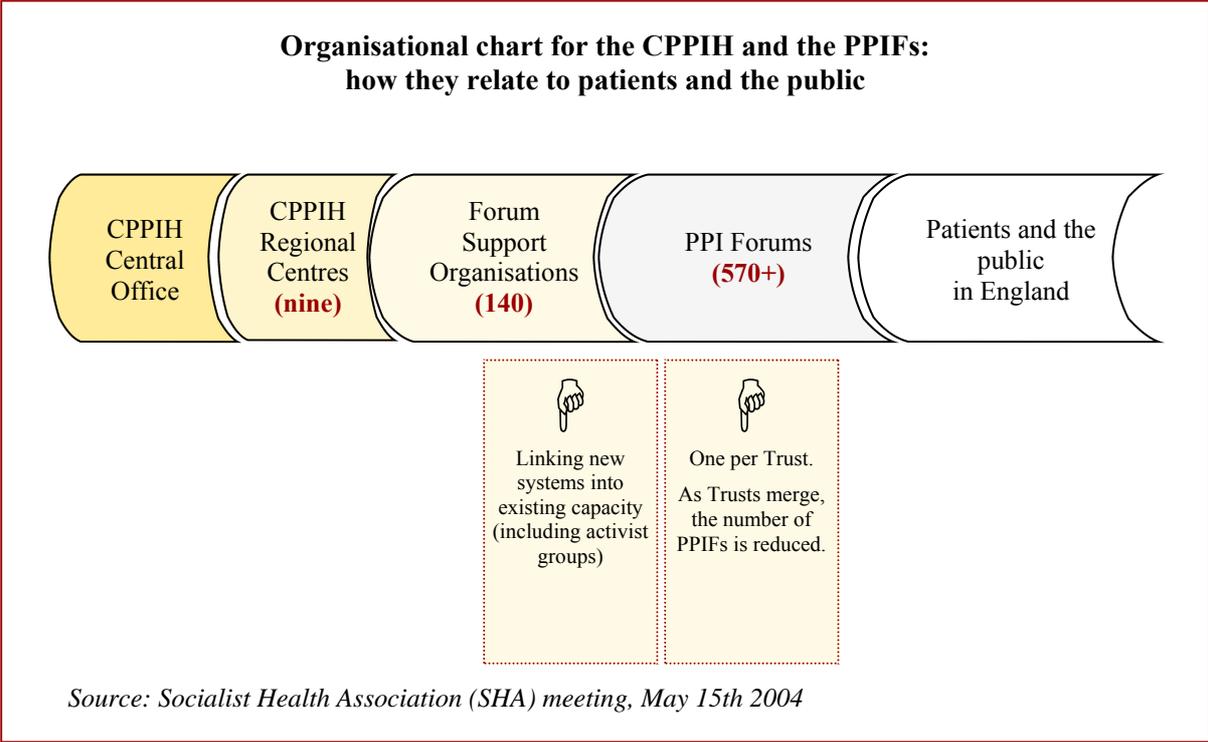


Several individuals with high profiles in the area of patient involvement spoke at the meeting

national efforts to report and learn from mistakes and problems that concern patient safety.

- Professor Jenny Popay, a Commissioner at the CPPIH and Professor of Sociology and Public Health at the University of Lancaster, England.
- Sally Brearley, Chair of [Health Link](#), a non-profit organisation whose role is to strengthen public influence in the NHS. Health Link canvasses the views of hard-to-reach groups within the population, so that they can be translated into improved health services.

Attending the meeting were a number of representatives from the CPPIH and the PPIFs, as well as NHS managers and members of the SHA.



Responsibilities of Patient and Public Involvement Forums (PPIFs) in the scrutiny and reform of the NHS

- Monitoring and review of services.
- Actively seeking views of wider constituents.
- The right to inspect PCT premises.
- The right to get a response to any public comment on NHS services.
- The right to recommend change.
- The right to gather information from the NHS.
- The right to raise concerns with more senior NHS management (or appropriate material body).
- The right to refer matters to the local Overview and Scrutiny Committee (OSC).

PPI Forums within PCTs have two additional jobs:

- Promoting user involvement in decisions affecting health services.
- Introducing public views into local NHS policymaking.

Source: Socialist Health Association (SHA) meeting, May 15th 2004.

The CPPIH is controversial because it replaces an older and well-regarded entity

The SHA meeting pointed out that the formation of the Commission for Patient and Public Involvement in Health (CPPIH) and the network of Patient and Public Involvement Forums (PPIFs) was controversial because, on December 1st 2003, these two new sets of organisations replaced a much older, and greatly-loved, system of Community Health Councils (CHCs). The CHCs had been established as long ago as 1974 to act as patient advocates within the NHS. Up until 2003, they had held the banner for patients at the NHS, ensuring their complaints were taken seriously. CHCs could call upon more than 5,000 volunteer members, who, functioning as unpaid watchdogs for NHS patients, contributed time generously. Despite their popularity, CHCs were abolished, explained Lord Hunt at the SHA meeting, because they had not really managed to change the prevailing culture within the NHS. Three decades of work by the CHCs had failed to persuade the health service of the importance of embracing its users' views.

The CPPIH is an ambitious entity

The Commission for Patient and Public Involvement in Health (CPPIH) and the Patient and Public Involvement Forums (PPIFs), on the other hand, were ambitious entities from the start. Their remit specifically required that they ask the NHS to adopt a unique and challenging new approach toward scrutiny and policymaking. The CPPIH, in fact, represents the first true, practical effort by any European government at introducing user-directed health reform. In effect, the CPPIH was to be one of the Government's key tools for transforming the NHS from a top-down management culture to a bottom-up one. Some of the characteristics espoused by the organisation include:

- **Consultation to be replaced by user involvement.** Section 11 of the Health and Social Care Act of 2001 made patient consultations and patient involvement a statutory duty in just about every action the NHS takes. To date, the NHS has

The organisation espouses user involvement

The CPPIH and its Forums were conceived as a tool to help the Government change the NHS

The organisation is aims to be a channel for the patient voice

The CPPIH is independent from the NHS ...

regularly consulted with patients through surveys and opinion polls. However, until Section 11 was created, the patient and public voice could find no direct mechanism for effecting change and playing an active part in the task of improving NHS services. The CPPIH, through its nine regional offices, 140 local network providers, and 570 PPIFs were tools intended to encourage user involvement. As part of this effort, the CPPIH launched its Knowledge Management System (KMS) in July 2004, a web-based virtual network for everyone interested in and involved with PPIFs [see box on page 13].

- **Empowerment of users.** The CPPIH was conceived as a conduit for public and patient opinion, to ensure that users' views could contribute to the important process of reshaping the NHS. Instead of being dictated to from on high, as was usual, the patient voice was at last afforded a channel—the CPPIH—through which to filter opinions upwards into the realms of central planning. Building up expertise in the PPIFs was seen as a way of tackling local health and social inequities.
- **Independence from the NHS.** The CPPIH was created to be an independent body, run separately from the NHS. The Patient and Public Involvement Forums lie outside the jurisdiction of the NHS Trusts—unlike the PALS, whose budgets are allocated by the Trusts. The NHS Reform and Health Professionals Act of 2002 also accorded the CPPIH enough legal powers to do their job properly. Members of the PPIFs, too, have statutory right—such as the right to inspect healthcare premises, demand explanations for concerns raised by users, and to refer matters to local-government Overview and Scrutiny Committees (OSCs), so that action can be taken.

The Commission for Patient and Public Involvement in Health (CPPIH) was one of the Government's key tools for transforming the NHS from a top-down management culture to a bottom-up one

The Socialist Health Association

According to its website, the UK Socialist Health Association (SHA), which is affiliated to the UK Labour Party, promotes health and well-being and the eradication of inequalities in the UK and worldwide “*through the application of socialist principles to society and government*”. SHA members argue that these objectives can best be achieved through collective, rather than individual, action. Underlying the SHA goals are three key themes:

- Democracy, based on: a) freedom of information; b) election, not selection,; and c) local decision-making.
- Equality, based on: a) equality of opportunity; b) affirmative action; and c) progressive taxation.
- Universal healthcare that: a) meets patients’ needs; b) is free at the point of use; and c) is funded through taxation.

The SHA believes that patients should, whenever possible, be active patients. The SHA states: “*People are experts in their own health. The clinician/patient interaction should not be defined as a customer/provider relationship, but as a co-production of equal partners. The new statutory rights for patients and users (contained in the Health and Social Care Act 2001 and the Race Relations (Amendment) Act 2000) to influence the planning and delivery of healthcare are welcome as a potentially powerful means of achieving the patient-centred health service envisaged in The NHS Plan. However, the mechanisms of this influence, such as local authority overview and scrutiny, and patient and public involvement forums, must be properly resourced.*”

... and covers
a broad
health-related
brief

The May
2004 Socialist
Health
Association
meeting
explains some
of the
CPPIH’s
problems

- **Health, not healthcare.** The CPPIH activities extends beyond mere healthcare. The organisation was also charged with improving the general health of public and patients alike.

Teething troubles

Soon after the CPPIH was formed in 2003, however, the organisation found itself dogged by difficulties. At the above-mentioned May 2004 meeting arranged by the SHA (itself an advocate for local healthcare governance), participants insisted that the CPPIH management was in disarray. The organisation’s Forums lacked a sense of clarity about how they should manage themselves. And most of the CPPIH’s local bodies—such as the Overview and Scrutiny Committees (OSCs) and the PPIFs—did not possess the resources to do their jobs properly.

Comments made about the CPPIH at the SHA meeting included:

- “*OSCs are already overstretched.*”
- “*PPIF volunteers have no clear, established lines of communication. Nor do they have any authority mechanisms by which to gain a consensus and understanding of the machinery of local government.*”
- “*There is an overlap of duties between PCTs and PPIFs regarding scrutiny.*”
- “*Many Trusts do not believe in the positive value of the Forum Support Organisations (FSOs).*”
- “*The CPPIH has not acted as a voice for patients at all. It has merely acted as a device for managing the establishment of forums.*”

**The meeting
thinks the
Government
is reluctant to
devolve
power locally**

**Even critics
allow the
CPPIH time
to make its
mark**

**A bombshell
hits the
organisation**

Some of the attendees at the meeting also doubted that central government would truly be willing to relinquish its control over the NHS to local bodies:

- *“The Treasury is reluctant to hand over money to local bodies. Local government needs proper resources available locally.”*
- *“Civic democracy does not figure in the current government’s approach to local government.”*
- *“Forums need muscle.”*
- *“Forums need their own budget.”*

Even the CPPIH’s critics at the meeting, however, were willing to concede that the CPPIH, at only one year old in May 2004, could hardly have had enough time to prove itself.

The CPPIH is abolished

Then, on July 22nd 2004, a bombshell hit. The Labour Administration announced the abolition of the Commission for Patient and Public Involvement in Health—although the Forums were to be retained.

The closure formed part of a general process of administrative cost-cutting in healthcare. A gradual growth in the numbers of health-related ‘quangos’ had spurred the Government into launching an efficiency drive, axing a number of the so-called ‘arm’s-length

The ‘Knowledge Management System’ of the Commission for Patient and Public Involvement in Health

The CPPIH says that its new Internet-based ‘Knowledge Management System’ (KMS) provides “an open and transparent way of sharing knowledge and information.” Users of the KMS can:

- Discover other people’s opinions on health.
- Share knowledge.
- Participate in online discussions.
- Link to other individuals.
- Access information on health (in the form of reports, surveys, and documents).
- And follow the activities of the Patient and Public Involvement Forums (PPIFs) and the CPPIH.

The ‘topic tree’ on the site has five main subjects available for users to browse:

- Conditions and treatments.
- Decision-making.
- Topical health-related issues.
- What affects health?
- And a ‘Shaping Health’ network.

http://www.cppih.org/about_kms.html

**A
Government
cost-cutting
exercise takes
in the CPPIH**

**A July 2004
Government
press release
speaks of a
reduction in
bureaucracy**

**The CPPIH
itself is
appalled by
the news of
its closure**

bodies' linked to the Department of Health (DoH). The CPPIH was one of many 'arm's-length' agencies and authorities to be told that they were going to be swept out of existence. [see table on next two pages].

In a press release issued by the DoH, the National Director for Patients and the Public, Harry Cayton, stated that that the government remained committed to an NHS centred on patients. Mr Cayton said that he looked forward "*to seeing the savings and the reduction in bureaucracy arising from the changes being translated into benefits for patients and frontline staff.*" [Dr John Reid, Secretary of State for Health, '*Reducing NHS Bureaucracy to Release Resources to the Frontline*', DoH Press Release, July 22nd 2004.] According to a DoH report, *Reconfiguring the Department of Health's 'Arm's-Length' Bodies*, DoH, July 22nd 2004, the PPIFs would be provided with new forms of administrative support from another DoH body or network—which had yet to be named when this issue of *HSCNews international* went to press.

The move to end the CPPIH was universally seen as controversial. On July 22nd 2004, Sharon Grant, Chairperson of the CPPIH, wrote in the organisation's own press release:

"I believe that these proposals will be seen as betraying the Government's promises to provide an independent voice for patients and the public in health. There has been no consultation with anyone about these proposals—either with the CPPIH, the 600 Patient Forums, or with the large number of patient and consumer organisations who fought so hard to set up the new system. Instead, we have a set of proposals which I believe will seriously weaken the patient's voice. They make little sense if there is a genuine commitment to bringing the public into health, and to achieving the culture change which is essential to addressing the nation's health problems for the future." [*'Arm's-Length Bodies Review Proposals Threaten Future of Patient and Public Involvement Says CPPIH Chair*', CPPIH Press Release, July 22nd 2004.]

The CPPIH will continue to function until the hand-over to a new overarching agency that will assume responsibility for the PPIFs.

*On July 22nd,
the Government
announced the
abolition of the
CPPIH, which
saw the move
as an act of
betrayal*

... continued on page 17

'Arm's-length' bodies (July 2004): <i>their future</i> —as determined by the UK Government's July 2004 review			
	Running costs (£m)	Number of staff	Fate
CHI: Commission for Health Improvement	36.6	376	Abolished 31 Mar 04
CPPIH: Commission for Patient and Public Involvement in Health	23.7	150	☹
CRHP: Council for the Regulation of Healthcare Professionals	1.4	3	☺
DPB: Dental Practice Board	23.9	325	☹
DVTA: Dental Vocational Training Authority	0.3	4	☹
FHSAA (SHA): Family Health Services Appeal Authority (Special Health Authority)	0.95	13	☹
GSCC: General Social Care Council	9.9	146	☺
HDA: Health Development Agency	13.1	132	☹
HFEA: Human Fertilisation and Embryology Authority	7.3	106	☹
HPA: Health Protection Agency	172.5	2,518	☺
IR: Independent Regulator of NHS Foundation Trusts	2.8	28	☺
MHAC: Mental Health Act Commission	3.9	45	☹
MHRA: Medicines and Healthcare products Regulatory Agency	55.9	747	☺
NBA: National Blood Authority	364.5	5,916	☹
NBSB: National Biological Standards Board	17.0	305	☹
NCSC: National Care Standards Commission	6.1	71	Abolished 31 Mar 04
NCAA: National Clinical Assessment Authority	133.9	2,726	☹
NHS AC: NHS Appointments Commission	4.3	46	☺
NHS CFSMS: NHS Counter Fraud and Security Management Service	13.4	250	☹
NHS Direct	120.0	2,000	☹
NHS Estates	29.5	218	☹
NHS IA: NHS Information Authority	204.8	918	☹
NHS LA: NHS Litigation Authority	11.2	182	☺
NHS Logistics Authority	64.6	1,377	☹
NHS Modernisation Agency	232.4	765	☹
NHS PA: NHS Pensions Agency	19.1	277	☹
<i>... continued on next page</i>			

<i>... continued from previous page</i>	Running costs	Staff numbers	Fate
NHS PASA: NHS Purchasing and Supply Agency	20.8	318	☺
NHS Professionals	33.0	671	☹
NHSU: Transforming Learning	27.9	234	☺
NICE: National Institute for Clinical Excellence	17.6	81	☺
NPSA: National Patient Safety Agency	17.0	149	☺
NRPB: National Radiological Protection Board	15.2	315	☹
NTA: National Treatment Agency for Substance Misuse	9.1	79	☺
PHLS: Public Health Laboratory Service	4.2	69	☹
PMETB: Postgraduate Medical Education and Training Board	3.0	27	☺
PPA: Prescription Pricing Authority	64.8	2,919	☹
ROC: Retained Organs Commission	1.2	18	Abolished 31 Mar 04
UKT: UK Transplant	10.5	121	☹
Others covered by review			
CSCI: Commission for Social Care Inspection	0.4 (estimate)	11	Operational as of 1 Apr 04
HC: Healthcare Commission	14.0 (estimate)	84	Operational as of 1 Apr 04
Health and Social Care Information Centre			Not yet operational
Blood and Transplant Authority			Not yet operational
Dental Special Health Authority			Not yet operational
NHS Business Services Authority			Not yet operational
NPfIT: National Programme for IT			Began operations in 2003
Regulatory Authority for Fertility and Tissue			Not yet operational
TOTAL NUMBER OF JOBS TO GO	6,185		
TOTAL BUDGET TO BE CUT	£500 million [740 million Euros; US\$ 914 million]		
☺ = long-term existence assured. ☹ = abolished, merged into another body, or to be made independent (privatised). <i>Source: Department of Health</i>			

... continued from page 14

**HSCNews
conducts a
'mini-poll' of
CPPIH staff
in August
2004**

**The survey
finds
confusion,
anger and
frustration
among the
people
running the
CPPIH**

**People within
the
organisation
were well
aware of its
management
problems**

HSCNews international samples CPPIH and PPIF opinion

To obtain an internal reaction to the announcement that the Commission for Patient and Public Involvement in Health was to be wound up, *HSCNews international* conducted a mini-poll of the organisation's employees and the recruits to the PPIFs (people from both categories are members of HSCNetwork international). The poll was carried out by email during the first two weeks of August 2004. Most respondents expressed outrage at the Government's action. Comments included:

- *“When the review of ‘arm’s-length bodies’ was announced, the view here was that we are a new body—therefore, the government would not touch us. Some people, however, were of the opinion that the CPPIH was only set up as a temporary measure, to dampen the controversy surrounding the closure of Community Health Councils (CHCs). When, towards the end of May 2004, we became aware of the danger, we believed that we would probably be taken over by the Healthcare Commission—which would then adopt the regional structure of the CPPIH. As it happens, the situation is a lot worse than that. It seems that, despite reassurances, the Government is uncertain about the whole public and patient involvement agenda. Perhaps the Government fears that too many powers have been given to the public and patient involvement forums. Whatever the reason, any successor is going to struggle to match the record of the CPPIH. We have been able to reach out to the most excluded and marginalised groups in society. The NHS Appointments Commission has no experience of doing this. There is a lot of anger among CPPIH staff. Many people have only recently been appointed—having left relatively secure jobs (for example, in local government) to join the Commission. Opportunities for people may occur in any successor set up, but there are so many uncertainties.”*
- *“I feel very concerned about the future of the CPPIH, and about health-related matters and the disabled, because so many people cannot afford private healthcare. I no longer know which direction healthcare is headed—the goalposts keep being moved about.”*

A few of the CPPIH staff who responded to the *HSCNews* mini-poll acknowledged the management difficulties experienced at the CPPIH and its related organisations:

- *“I assumed that the CPPIH had embraced a form of ‘matrix management’, in which people reported to their national functional leads [CPPIH central office] and liaised with regional colleagues and managers. When I asked around, though, no one seemed to have had heard of matrix management. Instead, there are two competing hierarchies at the CPPIH—one led by central office, and one led by the Regional Directors and the Regional Managers. It was up to the individuals concerned in the CPPIH to manage their time and the competing demands from these hierarchies.”*

Campaigners worry about the end of the CPPIH

The King's Fund believes that patient involvement is now in disarray

The CPPIH has a critical role, says the Consumers' Association

The Parkinson's Disease Society fears damage to patient involvement

What campaigners are saying

Health campaigners and activists are worried about the loss of the CPPIH—though not because they felt especially wedded to the Commission itself. Rather, they see its demise as yet another reminder that most state-run healthcare systems are unhappy with the whole concept of patient/public-driven healthcare systems and with any genuine attempt to devolve healthcare to local levels.

“Abolishing the CPPIH leaves the whole question of patient and public involvement in health in disarray”

Niall Dickson, chief executive of the [King's Fund](#), put the matter succinctly when he stated in a press release on the subject: *“Abolishing the CPPIH leaves the whole question of patient and public involvement in health in further disarray. The current range of piecemeal policies does not add up. They are bewildering to those who work in the NHS, and a complete mystery to the public. Today's announcement will simply add to the confusion.”* [*‘Patient and Public Involvement in Disarray, Warns King's Fund in Response to Cull of NHS Arm's-Length Bodies’*, King's Fund Press Release, July 22nd 2004.].

Other consumer and patient organisations echoed these sentiments. Quoted in *The Guardian* newspaper, Frances Blunden, principal policy adviser to the UK [Consumers' Association \(CA\)](#), said that by getting rid of the CPPIH without any public consultation, the Government was ignoring the critical role the Commission had been set up to fulfil. [David Batty, ‘Anger as Axe Falls on Patient Watchdog’, *The Guardian*, July 23rd 2004.]

The [Parkinson's Disease Society \(PDS\)](#) of the UK expressed concern that *“the abolition of the CPPIH will undermine the involvement of patients in local health services.”* A PDS press release stated: *“Following the abolition of the Community Health Councils (CHCs) in England, the CPPIH was introduced to ensure an independent voice for patients and the public in health services. It has underpinned the setting up of the local Patient Forums. The PDS believes that the views of patients should be heard, and calls on the Government to announce—without delay—how the work of the CPPIH will be maintained in the future, and demonstrate commitment to ensuring that patients remain at the heart of the NHS.”* [*‘Parkinson's Disease Society Voices Concerns Over UK Government's Abolition of Patient Involvement’*, PDS Press Release, July 23rd 2004.]

Some of the bodies to have reacted to the news of the CPPIH's demise

The King's Fund

An independent charitable foundation working for better health, especially in London. The organisation carries out research, policy analysis, and development activities, working alone or in partnerships, and through grants. The King's Fund is also a major resource to people working in health, offering leadership and education courses, seminars and workshops, publications, information and library services, and conference and meeting facilities.

The Consumers' Association (CA)

Founded in 1957, the Association conducts research and campaigns on behalf of consumers. With over 700,000 members, the CA is the largest consumer organisation in Europe.

The Parkinson's Disease Society (PDS)

The Society organises and supports a range of national and local campaigns throughout the UK to improve the quality of life for people with Parkinson's, their families and carers. The PDS seeks to influence health policy throughout the UK to ensure that the needs of all people with Parkinson's are met. The group also funds research into the cause of Parkinson's, and research aimed at improving current treatments and care techniques. It offers a range of services and resources, providing support to all people with Parkinson's, their friends, families and carers.

What next?

Clearly, the question currently vexing people who represent the interests of patients and the public in England is whether the UK Government has abandoned its ambitious, patient-oriented agenda, and settled for a more pragmatic and safer NHS, in which the influence of patients is far more limited?

“Perhaps the time has come to argue for a patients’ parliament?”

The Socialist Health Association is pessimistic about patient expression

Health Link is less so ...

Martin Rathfelder, Director of Development at the SHA, believes that the time might be right for the grassroots to find their own solution for better patient representation in NHS affairs:

“The key problem is how this work will fit in to whichever quango they give the PPIFs. Most of these organisations would like control of their own budget, for a start—and possibly their own staff. Even if these benefits were passed to the PPIFs, it is still difficult to see how patient’s voices are to be expressed nationally. Perhaps the time has come to argue for a patients’ parliament?”

Sally Brearley, Chair of Health Link and former Vice-Chair of the Association of Community Health Councils for England and Wales (ACHCEW), suggests that the people working in patient involvement at the coalface remain active—but they do need to be given money and powers:

“The abolition of the CPPIH does not imply an end to patient involvement. We are in the early stages of a reform of which CPPIH

**... and
considers that
patient
involvement
has a future
at the local
level**

was merely one component. There is an opportunity to redirect resources, making Patients' Forums the real drivers of the new system of patient and public involvement. This was the intention of policy-makers from the beginning. The CPPIH has put Forums in place, but it has also created a system which is too bureaucratic and top-down. Giving Forums good staff support, their own budget and premises will help them deliver their core function: effectively monitoring their local NHS. We do need a national voice for Forums, but this can be achieved without the CPPIH—by bringing Forums together to speak for themselves.”

The next issue of *Health and Social Campaigners' News international*

Issue 10 of *HSCNews international* (September 2004) will examine how campaigners use e-technologies.

Back issues of *HSCNews international*

Issue 1 (November 2003)

- ✓ Disability groups campaign worldwide for human rights for people with a disability.
- ✓ Stem cell research splits the world of patient advocacy.
- ✓ Campaigners in the US, Canada and New Zealand take opposing sides on the DTCA issue.
- ✓ Three overarching patient umbrella groups are created in Europe.

Issue 2 (December 2003)

- ✓ Campaigners for affordable medicines scored huge successes against governments and pharmaceutical companies worldwide in 2003. Groups' budgets reach billions of dollars. New targets are likely in 2004.
- ✓ The men's health movement has moved beyond issues of sexual health, and is now a global force.
- ✓ Interview article: 'The Men's Health Forum: A Model for Campaigning Groups?', with Dr Ian Banks, chief executive. The group is expanding, widening its range of funding, and helping similar bodies overseas.

Issue 3 (January 2004)

- ✓ Campaigning groups are gradually moving closer on the DTCA issue in Europe. But significant divisions remain between them. Debate is likely to focus on a potential information 'police force' in 2004.
- ✓ Interview article: 'Active Citizenship Network's European Charter of Patients' Rights', with the group's senior executives. ACN is running perhaps most ambitious healthcare project of any advocacy group—an attempt to incorporate a 14-point charter of patients' rights into all European countries during 2004.

Issue 4 (February 2004)

- ✓ Global standards of provision for mental healthcare are poor in comparison with those aimed at more high-profile diseases. Yet new medicines and psychotherapies can treat even the severest mental health conditions. Campaigners across the world are lobbying policymakers for reforms to outdated mental health services.
- ✓ Interview article: 'The battle against stigma—the experience of US group, Stamp Out Stigma', with the group's founder, Carmen Lee. SOS uses speaker bureaus, presentations, toolkits, and lobbying to publicise the damaging effects that stigma can have on people with a mental health problem.

Issue 5 (March 2004)

- ✓ Campaigning groups are joining forces with academic researchers to vehemently lobby against the EU Clinical Trials Directive. Campaigners say that the legislation will destroy non-industry trials in Europe.
- ✓ Interview article: 'The James Lind Alliance', with one of the group's founders, Sir Iain Chalmers. The JLA, formed in April 2004, will use patient-clinician partnerships to confront important treatment uncertainties.
- ✓ Part II of a series on mental health looks at campaigns in three mental health conditions—depression, dementia, and bipolar disorder. Also examined: the controversy over SSRIs; and NICE's relationship with campaigning groups.

Issue 6 (April 2004)

- ✓ The current crisis in the funding of health campaigners. Sources of funding of campaigning groups in the US, Canada, Europe, UK and Australia.
- ✓ Interview article: The Taproot Foundation was created to help non-profitmaking groups of all types (including those in the field of healthcare) gain the professional business tools needed to build robust ongoing concerns.

Issue 7 (May 2004)

- ✓ The latest in the campaigns for affordable medicines. After vigorous lobbying, campaigners have claimed at least three major victories in the first half of 2004.
- ✓ Interview article: Médicos Sin Fronteras Argentina has had to tackle the question of whether its role might be compromised by involvement in a politicised trade debate about access to affordable medicines.
- ✓ An April 2004 meeting by Mental Health Europe explains key initiatives on how to end healthcare services' discriminatory practices against people with psychosocial disability.

Issue 8 (June 2004)

- ✓ Regulating children's medicines. The experience in the US and forthcoming changes in EU law.
- ✓ Interview article: Asociación Española Contra el Cáncer (AECC), one of Spain's largest patient organisations, undergoes a strategic review.

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