Developing Clinical Governance for Complementary and Alternative Medicine in Primary Care

Seminar 3: Effective Patient, Carer, and Public Participation

Report written by Caroline White
Key Contributors: Ray Davies, Christine O’Connor, Roy Jones, Professor David Peters, Dr Peter Smith, Bob Sang, Jane Wilkinson

Thursday March 27 2003 - King’s Fund, London
## Contents

3.1 Introduction  
Professor David Peters, Clinical Director, School of Integrated Health, University of Westminster and Christine O’Connor, Director, Catch On (consulting)  

3.2 Patient participation in the context of primary care  
Presentation I: Dr Peter Smith, Chair National Association of Primary Care  

3.3 Developing strategies to involve patients, carers, and the public:  
Presentation II: Bob Sang director Sang Jacobsson Limited  

3.4 Creating expert patients:  
Presentation III: Roy Jones, independent consultant in self management  

3.5 MIND and the CHI project:  
Presentation IV: Ray Davies, project manager MIND-CHI collaboration  

3.6 Questions and Answers session  
Facilitated by Christine O’Connor, Director, Catch On (Consulting)  

3.7 Achieving patient involvement  
Workshop 1: Facilitated by Christine O’Connor, Director, Catch On (Consulting)  

3.8 Patient ownership and concordance care plans/goals for empowerment  
Workshop 2: Facilitated by Christine O’Connor, Director, Catch On (Consulting)  

Glossary  

Appendix i Seminar participants  
Appendix ii Self efficacy academics dealing with Medical Issues and Settings, Clinical issues and Health  
Appendix iii Achieving patient involvement: Workshop 1 groupwork and feedback  
Appendix iv Patient ownership and concordance care plans/goals for empowerment: Workshop 2 groupwork and feedback
Sixty-two participants from across England contributed to the consensus-building day. They represented a range of organisations, including PCTs, CAM professional/accrediting organisations, patient groups, service providers and academic institutions. Thank you to all the delegates, speakers and rapporteurs for your time and contribution. A list of participants can be found in appendix i.

3.1 INTRODUCTION

Professor David Peters, Clinical Director, School of Integrated Health at the University of Westminster

Christine O’Connor, Director, Catch On (consulting)

Professor Peters began by stating that clinical governance was about "creating a mind, a memory, and intelligence for our practice." The seminars, he said, were about building quality into complementary medicine delivery.

One of the seven pillars of clinical governance was about public and patient involvement, added Christine O’Connor, in her introduction. Patients were the “nub of the matter” but following through was challenging for all.

Christine pointed out that national insurance changes from April 1 would make everyone a shareholder in the NHS. For example, a person earning £20,000 a year would now have to pay £250 a year to invest in the health service alone in additional NI charges.

That degree of investment makes the whole issue of patient involvement much more critical, she said. Users are entitled to have a greater voice and to know how that money is being spent
3.2 PATIENT PARTICIPATION IN THE CONTEXT OF PRIMARY CARE
Presentation I: Dr Peter Smith, Chair National Association of Primary Care

We all think we know what patient participation is, but the reality is that we all probably know a little bit of it, and we all think it must be appalling because we are not able to participate fully, and tend to project that across the NHS as a whole.

This is partly because we are only really just starting out on this, even if it feels as if we have been doing it for a long time. However, is also possible to do something really positive because we are at such an early stage.

Changes have been very recent, illustrated by the Department of Health policy guidance which was only published in February: *Strengthening Accountability: Involving Patients and the Public*.

In that document David Lammy, Parliamentary Under Secretary of State for Health, makes several points/recommendations:

- Make sure the NHS delivers patient centred care
- Involve and consult patients and the public in health service planning and delivery
- Patients’ views about their experiences of the National Health Service should be welcomed, taken seriously, and used to inform change
- Patients and the public rightly expect to be involved and consulted in all aspects of their lives
- More people want to “have a say” in decision making
- Public authorities are more open to scrutiny and challenge

Involvement is not an end in itself; it’s about delivering care in a new way.

<table>
<thead>
<tr>
<th>The purpose of involvement:</th>
</tr>
</thead>
<tbody>
<tr>
<td>strengthening accountability to local communities</td>
</tr>
<tr>
<td>health services’ improved responsiveness to patients and carers</td>
</tr>
<tr>
<td>developing a sense of ownership and trust</td>
</tr>
</tbody>
</table>

It is also about empowerment, in the sense that getting patients involved in their own health produces better outcomes.

<table>
<thead>
<tr>
<th>Some of the cogs in the patient involvement wheel:</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Commission for Public and Patient Involvement in Health (CPPIH) underpins most of the other elements of participation in the NHS, but at the moment few people know what it is.</td>
</tr>
<tr>
<td>Patient Forums are very different from PALS (Patient Advice Liaison Service), because they are about starting to affect ways in which care is delivered, rather than complaining about it afterwards</td>
</tr>
<tr>
<td>ICAS (Independent Complaints Advocacy Services) replace Community Health Councils’ advocacy role</td>
</tr>
<tr>
<td>PALS</td>
</tr>
<tr>
<td>Oversight and Scrutiny Committees will address democratic accountability at local level</td>
</tr>
<tr>
<td>Expert patients</td>
</tr>
<tr>
<td>Patient choice, but at the moment it only applies to people requiring heart surgery</td>
</tr>
</tbody>
</table>
Patient fora:

- Made up of 9 to 15 members and contain mostly users
- Represent the views of local communities about local services
- Monitor service delivery from the patient's perspective
- Inspect every aspect of care used by NHS patients, including primary care and independent care
- Elect one of their members as a non-executive director on trust board; a member will also join the Oversight and Scrutiny Committee panel
- Monitor the quality of PALS in the area
- Monitor the quality of ICAS in the area, flagging up problems to CPPIH

Patient fora will be powerful and could begin to address the lack of local democratic accountability.

The stages of participation

Ruth Chambers wrote a chapter on the stages of patient participation in The Handbook of Primary Care Trusts.¹

Stages of patient participation

- Information exchange, which means that both sides offer it, but there is no negotiation and no shared view
- Consultation, whereby the patient expresses a view, but the consultant still makes the decision
- Support, whereby the patient decides what to do and others support him/her to do it
- Deciding together, which means thinking and planning together
- Acting together, which means implementing plans together

The health service is still in the early stages of participation, both in terms of the consultations health professionals have with patients, and in terms of the way in which health care is delivered generally.

There are several different levels of participation. Before the patient/client comes to see a doctor, they may want a certain amount of advice. Who they turn to becomes important. That's not about sickness, that's about health and how to maintain it.

Beyond that, complementary therapies start to come in. There has been a lot of discussion so far about shifting care from one professional to another, without perhaps considering that the patient can do plenty for him/herself at this stage and can be empowered to do so.

The consultation is particularly important in terms of clinical governance. How far is the patient empowered in consultations?

When it comes to being involved in service design/delivery/strategic overview, this is extremely hard to do, even at a local level.

The European experience

Graham Lister from the College of Health compared four different countries in this respect: the Netherlands; Germany; Denmark and Finland.

Findings from the College of Health:

- Dutch policies emphasise patients’ civic rights, so there is a good deal of support for patient organisations and information systems, stimulating participation in healthcare.
- German policies puts the focus on the rights of the insured, obliging insurance companies to make provision for the support of self care as an integral part of patients’ rights.
- The Danish emphasis is on outcomes, and has changed from the rights of people to maintain their health at home to strategies for improved health status.
- The Fins target the need to improve health, with support for nurse led community groups and family initiatives.
- All these countries enjoyed local and regional democratic input into healthcare and all four provided some independent funding for patient involvement. This is beginning to happen in the NHS, but it is still very much in its infancy.
- All the countries made a distinction between patient and consumer involvement and the democratic choices in health.
- The English NHS is the least democratic of all the systems he studied.

There is still a huge local democratic deficit within the NHS, but it is not all bad.

Helen Magee, of the Picker Institute, studied several different European countries (telephone survey, August 2002: Switzerland, UK, Italy, Sweden, Germany, Slovenia, Poland, Spain), and asked about whether patients were sufficiently involved in treatment decisions.

The UK included 1000 patients, and surprisingly, came second only to Switzerland, with around 80% thinking there was sufficient involvement. Spain came bottom with 50%. So, there may not be a democratic input, but people seem to feel involved. They also looked at access to self care and complementary medicines.

Picker Institute, public opinions on the level of patient involvement:

**Germany:**
- Many complementary therapies are covered by health insurance schemes, so they are fully integrated.
- In 1999 Germans spent DM 678 million on vitamin preparations.
- Of the 1.6 billion medication packs available, almost half are for self-medication

**Italy:**
- Italians are bottom of the league for CAM, and doctors take a very paternalistic approach, with little integrated care.
- A 1988 survey revealed that 61% thought medicines should be used only under close medical supervision and 41% believed medicines were too easily available.

**Poland:**
- A 1997 survey indicated that 65% used self medication to treat minor problems.
- A 1998 survey revealed that 40% rely on home remedies, but it’s not clear whether these are CAM.

**Slovenia:**
- CAM is not officially recognised.
- A telephone survey in 2001 showed that people knew very little about self care and that people chose inappropriate treatments because they got poor advice from the local pharmacy.

**Spain:**
- A 1997 survey indicates that most respondents use only drugs prescribed by their doctor
- Legislation restricts dispensing of drugs without a prescription
- Local studies suggest an increase bacterial resistance to antibiotics associated with self medication.

**Sweden:**
- Self medication is widely practised
- Complementary medicines are regulated
- The market for natural remedies was worth 1.6 billion Swedish Crowns in 2000.
Switzerland:
- CAM courses are taught in five medical schools
- One in four drugs (26%) is available without prescription
- Self medication is practised by 40% of the population, and increases with age

UK:
- There is a considerable amount of self care, but there are concerns about the provision of strong drugs without a prescription
- Patients who are exempt from prescription charges are more reluctant to buy treatment over the counter
- The use of CAM is predicted to increase, in no small part due to the work of the Foundation.

In summary, the UK is not starting off from a very poor baseline. Across the whole of Europe, it is very clear that self care and the use of CAM is increasing dramatically, despite variations. The patient-doctor relationship is still central, but there is an increasing sense of personal responsibility for health.

There are vast numbers of different patients with diverse needs, and meeting those needs in any one setting can be difficult.

**Demonstrating patient involvement**

“I hold that the very purpose of existence is to reconcile the glowing opinion we hold of ourselves with the appalling things that other people think about us.” Quentin Crisp

Doctors have a tendency to think they are doing a wonderful job, but patients do not always see it that way. The difference is that it is no longer acceptable for them to hide in bunkers and ignore the criticisms.

The new General Medical Service contract stipulates that the patient experience will be an important part of service delivery (and quality payments).

**Examples of quality payments, new GMS contract:**

- Length of consultation: 30 points
- Patient surveys (annual): 40 points
- Acting on patient surveys: 15 points
- Discussing the results of the survey with a patient group or NED, proposing appropriate changes, and providing evidence for their enactment: 15 points

There are 1000 quality points, 10% will be accumulated around the patient experience. This can include everything from whether the doctor was nice to the patient to whether surgery has chairs and magazines in it.

**Quality points are comprised of:**

<table>
<thead>
<tr>
<th>Category</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical:</td>
<td>550</td>
</tr>
<tr>
<td>Organisation:</td>
<td>184</td>
</tr>
<tr>
<td>Added services:</td>
<td>36</td>
</tr>
<tr>
<td>Quality practice:</td>
<td>30</td>
</tr>
<tr>
<td>Holistic care:</td>
<td>100</td>
</tr>
<tr>
<td>Patient experience:</td>
<td>100</td>
</tr>
</tbody>
</table>
3.3 DEVELOPING STRATEGIES TO INVOLVE PATIENTS, CARERS AND THE PUBLIC:
Presentation II: Bob Sang director Sang Jacobsson Limited

“How would it be some power could give us the chance to see ourselves as others see us.” (Robert Burns).

The notion of patient involvement is essentially about how we see ourselves and our health. That is why effective patient participation in relation to CAM represents the constructive convergence of two social movements, both of them passionate about human welfare.

In integration of CAM we are witnessing more than a clinical/professional/practice movement. This is the construction of a social movement. It is about people who see themselves in health in a very powerful way. The popularity and appeal of CAM has been patient-led; patient centred-ness and participative intent are inseparable facets of the CAM ethos and they have been powerful factors in its growth.

Another social movement - concerned with democratic deficit - has its roots far back in history. The Levellers and Diggers in Jacobean times, who were looking for a more democratic society; Thomas Payne, who tried to create a civic society where everyone had a say, are examples. Now this movement is going on in primary care.

Challenging the way in which patients see themselves

However, there is a tension amid this growing confidence, and that has to do with how we see ourselves. We can co-create better health, which requires seeing yourself as an asset, not as a person with needs, but that is difficult. It is difficult because it challenges the cultures of identity, self esteem, professional competence and confidence that are based on a social good - doing good. For CAM practitioners what matters are the quality and the health of the professional relationship. The notion of patient centred care is divisive. It needs to be equal.

Five years ago, I facilitated a citizens' jury on chronic back pain, which looked at how the health service could shift its investment away from traditional referral routes and work with GPs to extend the routes to chiropractors and osteopaths. The obstacles were enormous, but what was central to the healing process of people with back pain was the quality of their relationships with professionals and how those grew.

We are at the beginnings of a paradigm shift, a fundamental challenge to the way we think and practice, to the language we use, the nature of the relationships we have, and our symbols. One of those symbols is the local delivery plan, which each PCT has to produce.

What we mean by patient choice

At the moment, patient choice is about scheduling and logistics; it is not getting into the guts of issues about how and why we refer and the reasons behind people’s choices. We need to rethink our roles and work differently as practitioners and researchers.

When we begin to:

- Look at people as citizens and consumers
- View GPs working with practitioners (employees) as partners in the process of developing the system
- Recognise that exercising choice means taking a share of responsibility as well
- Understand mutuality that is needed for the quality of relationships

Only then will we move from a “doing to” culture to a “learning with” culture.
Practitioners have been saddled with a presumption of a risk-free process and a degree of certainty, when we know that the evidence base for all clinical practice is very limited, and is based on a gold standard, which cuts out what matters most - the relationship.

The user/patient movement has shifted away from doctor bashing and exploiting the divisions. People now have the opportunity to opt in as corporate citizens in decision making and become a constructive sounding board, and act as “critical friends,” co-designing planning and commissioning.

People can take on difficult, tough choices about priorities and shift the design, development, and delivery of local services, working as co-producers in better health. The active partnership that is possible through self-management and self-care is really powerful.

Bringing expert patients into monitoring and evaluation is particularly important for clinical governance.

What works?
- Why get involved? Ruth Chambers’ model is very helpful, but ignores the fact that we do not start with a blank piece of paper: we need to explore our motivations.
- It is important to involve local people from day zero in the design of the design, when planning the integration of CAM into primary care.
- It would be unhelpful for these new models to become institutionalised. The best involvement is temporary, ad hoc, and fit for purpose, rather like Jury Service.
- Involvement requires natural justice and equality principles (DDA, REA, due process). And the Freedom of Information Act will make this very relevant, because people will be able to ask about everything that affects their health.

• Working with people as peers. “Label jars, not people,” was a slogan developed by People First about those with learning disabilities.

• People learn through their experiences. Patients teach as much back to the practitioner and they teach patients about managing their health.

• Transparency, respect, listening and noticing states of mind (something that GPs are good at)

• What gets in the way are jargon, furniture (tables) between people, toolkits (surveys and focus groups), and meetings rather than working and learning together.

Remember: What happens when there is such a fundamental shift going on is that it creates mistrust and fear and people bring with them a legacy of cynicism and ‘loss’ where the system has failed them.

Questions to think about

• Are we going to get involved? If so, How? With whom? When?
• We need to think about the wider service partnership, including the members of our professional organisations.
• Where do we involve the suppliers, because a lot of treatment is bought off the shelf and heavily marketed?

We are at the beginning of a fundamental change, but we are still not looking at ourselves closely enough, and that is where the resistance/tension lies. If we are truly to move forward, we must overcome that. The words “fundamental cultural change” are often quoted, but will they be endlessly resisted?

---

3.4 CREATING EXPERT PATIENTS
Presentation III: Roy Jones, independent consultant in self management

In Dallas University Hospital, rheumatology patients were trained in the skills required for physical examination. They were then tested out as university staff. The results showed that the “patients” had better undergraduate attendance rates and better results not only from them, the registrars and the consultants as well.

Who are expert patients?
An expert patient is someone who:
- Has assessed the impact of chronic disease on their lives
- Has worked out the local service provision for practical and medical help
- Is determined to live a healthy life, despite their chronic condition
- Understands that they are primarily responsible for the quality of their lives

The roots of the movement
The concept of expert patients had its roots in the Patient Education Research Center (PERC) at Stanford University, California.

The United States Congress passed several arthritis acts in 1978, 1988, and 1998, and money was made available for patient education programmes. One of the centres to take it up was Stanford.

A British nurse, Kate Lorig, was employed and she published her patient education public health doctorate for people with arthritis in 1983, to great acclaim. It showed a reduction in anxiety, fatigue, depression and pain, as well as fewer visits to physicians and emergency care. Other benefits included an improvement in relationships with health professionals, carers, and family members.

The Arthritis Foundation took it up enthusiastically, and that enthusiasm was echoed in Australia and Canada, although not in the UK, because it was deemed to be “too American” and not suitable for Britain! Kate realised that arthritis was so widespread that the training could not be done by health professionals. So she designed the education programme to be delivered by people with arthritis.

Outside Stanford and South Bay San Francisco it is hardly ever delivered this way; almost without exception, it is done by a professional with a patient they have chosen.

Course content
- Principles of self management (identifying sources of help)
- Exercise, relaxation tailored to personal needs
- Problem solving, goal setting, contracting
- Cognitive symptom management, challenging negative thinking
- Dealing with strong feelings: anger, fear, frustration, depression
- Fatigue and pain management
- Eating well
- Communication with health professionals and family
- Medication (20 minutes only out of 6 sessions across a 6 week course: the reason for this is that there is no need to set up volunteers as experts in this; what is essential to know does not amount to a great deal.)

Many of the elements will be familiar to patients on pain management courses, and it contains elements of cognitive behavioural therapy.
In the UK....

- In Arthritis Care, the Stanford model was used, and exclusively with people who had arthritis.
- Course tutors with suitable backgrounds and chronic conditions delivered the training in pairs, following a manual, and subject to assessment and inspection.
- A course encompassed 6 weekly 2.5 hour sessions.
- The course tutors are themselves trained by trainers, all of whom also have chronic conditions, who are appointed by the Strategic Health Authorities or by partner voluntary agencies.

In the early days, it was not clearly understood why the results should be so positive. Was it sharing experiences? Was it using techniques as a toolkit? Was it greater knowledge of arthritis? The search began for a theory to explain how it worked. Albert Bandura, professor of social psychology, came up with *Self Efficacy: Toward a Unifying Theory of Behavioural Change* in 1977. Self efficacy is a construct within a social cognitive theory of human behaviour, which pulls ideas together. However it moves away from cognitivism—empowering by imparting knowledge.

You can not empower anyone by simply giving them knowledge, if they do not know how to use it, or feel they lack the confidence or status to use it. Unfortunately, the concept of cognitivism is very much alive in the NHS. The relationships between patients and doctors need to be about learning experiences.

Kate’s work was re-written in the light of Albert Bandura’s work. [www.emory.edu.education](http://www.emory.edu.education) provides an overview of what is going on around the world in self efficacy research, but there are only two British researchers involved, despite its rigorous scientific credentials. And it is not part of medical training.

“Self efficacy is the belief in one’s capabilities to organize and execute the sources of action required to manage prospective situations.”
Albert Bandura, 1986

---

**Self Efficacy**

Self efficacy beliefs are not about the concept of self, but about

- Judgment and confidence
- Sensitivity to context
- Being task specific
- Being made and used in reference to some type of goal
- Being domain specific
- A question of ‘can’ do

Self concept beliefs are about:

- Judgment of self worth
- They are not sensitive to context, not task specific
- Cognitive self appraisal independent of the goal
- They can be domain specific
- A question of being/feeling

Self efficacy influences

- The choices we make
- The effort we put forth
- How long we persist when we confront obstacles, and in the face of failure
- How we feel

---
In England the Expert Patients Implementation Group was set up in October 2001, and the principal trainers had been appointed by Easter 2002. There are now 65 senior trainers working in pairs scattered around strategic health authority areas, with over 700 volunteer course tutors being trained. By the end of March 2004, it is thought 18,000 people will have been through the process.

In the voluntary sector, expert patients have been part of Arthritis Care and the Long Term Medical Conditions Alliance, and the programme feeds into so many agendas – The Patient and Public Involvement PPI initiative\(^5\), Patient Advisory and Liaison Services\(^6\) (PALS), NATPACT’s \(^7\) ‘Engaging Communities Programme’.

The work at Stanford is supported by Kaiser Permanante, and that’s because this work is about keeping people in work and keeping families healthy.

**Why is the Expert Patients agenda gathering such momentum?**

It sounds as if the benefits are primarily for people with long term medical conditions, and there is indeed measurable evidence for this. UK research is only just getting going, but the work that Julie Barlow has done at Coventry shows very similar results to those from America. (Please see appendix 1 for full list of Self efficacy academics dealing with Medical Issues and Settings, Clinical issues and Health)

The secondary benefit is what happens to the people and their relationships. An important driver for the Department of Health is the reduction in GPs’ time, but one of the most powerful drivers is the desire of those who have been trained to help other people like themselves.

These are not the people who are already active in other organisations; these are people who have discovered that what they have had to learn the hard way is useful to other people. They’ve learnt how to put what they know into context, to share without dominating, to support each other. So in the end, it’s a citizen’s response.

**Possible problems**

- The greatest challenge at the moment is structuring these patients’ contributions into the healthcare system, and being able to sustain the momentum.
- The evaluation has not properly started yet, despite being well down the road. The research will therefore pick up on the programme half way through rather than from its inception.
- The sheer power of the cognitivist assumption is deeply ingrained and guides so much work.

Self managing patients enable health professionals to practise better medicine and they are themselves committed to doing things better.

Christine picked up on a quote from one of Roy’s slides: “We who cut mere stones must always envisage cathedrals.” She told the story of the three stone cutters, by way of explaining that perception is all.

A man walking along the road came across three stone cutters, to each of whom he asked the same question: “What are you doing?” The first replied, “I am just cutting stones.” The second said: “I’m earning a living to feed my wife and children”, but the third said: “I’m building a beautiful cathedral.”

\(^5\) [http://www.dh.gov.uk](http://www.dh.gov.uk) search for PPI  
\(^6\) [http://www.dh.gov.uk](http://www.dh.gov.uk) search for PALS  
\(^7\) [http://www.natpact.nhs.uk](http://www.natpact.nhs.uk)
3.5 MIND AND THE CHI PROJECT:
Presentation IV: Ray Davies, project manager MIND-CHI collaboration

MIND was awarded a three year contract to work with CHI in September 2002, during which time we aimed to recruit, train, and support, mental health service users to become expert patient assessors.

The relevance of this project is that when CHI becomes CHAI, it will take over roles currently taken by the Mental Health Act Commission, the National Care Standards Commission, and some parts of the Audit Commission. MIND is not only deeply committed to quality assurance, but it also provides services similar to those of CHI, because of its various networks.

MIND also felt that it was well placed to understand the importance of clinical governance reviews, and to offer a diverse range of reviewers pooled from these networks—MINDLink (service user arm) and Diverse MINDS (black and ethnic minority arm).

Recruitment and training
Adverts for potential tutors produced 1800 applications from mental health service users, although the contract stipulates only 50 for the first year. The project officers are all service users as well.

The training is intense, and includes an orientation day to outline the hard work involved, followed by a two-day training course provided by MIND, which if successfully completed, leads on to a further three-day training course provided by CHI, which is given to all selected assessors.

CHI's guiding principles
CHI aims to improve the quality of patient care in the NHS and address unacceptable variations in practice.

Its guiding principles are:
- The patient experience is its raison d'être
- Fairness, independence, rigour
- Developmental approach to achieve and sustain improvement
- Evidence based
- Openness and accessibility
- The same standards sought elsewhere are applied to CHI itself

All mental health trusts are currently reviewed at least once every four years, but the intention is to make the reviews more frequent and to incorporate elements of the Mental Health Act Commission work when the new CHAI begins its work.

The CHI vision of clinical governance
CHI defines clinical governance as:

"The systems of steps and procedures adopted by the NHS to ensure that patients receive the highest possible quality of care."

In its white paper A First Class Service, the government defined it as:
“A framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish."

The review therefore covers the seven pillars of clinical governance:
- Consultation and patient involvement
- Clinical risk management
- Clinical audit  
- Research effectiveness  
- Staffing and staff management  
- Education, training, and continuing professional development  
- Patient experience

CHI states that effective clinical governance should therefore ensure:
- Continuous improvement of patient services and care  
- A patient centred approach that includes treating patients courteously, involving them in decisions about their care and keeping them informed  
- A commitment to quality, which ensures that health professionals are up to date in their practice and properly supervised where required  
- The prevention of clinical errors the commitment to learn from mistakes and share that learning with others.

The review process
All reviews are published on the CHI website and are available from local libraries. However, it is only in the past year that CHI has started reviewing mental health trusts, and it is due to start reviewing PCTs later this year. A CHI review takes place over 17 weeks, and during the preceding 3 months, a trust will be asked to provide information to CHI.

About three weeks into the actual review, a stakeholder week takes place, which is where mental health service user assessors first become involved. They interview patients, using a questionnaire, developed with MIND input. The information from this is then used for the two briefing days. During stakeholder week, a review manager, employed by CHI, holds open fora, which anyone can attend. Information gathered from this is also brought to the briefing days. The stakeholder week is followed by a peer review week, with a team of 8 to 12 assessors, working in pairs. They can, and do, interview anyone at a trust, from the chief executive to hospital porters.

All the information from the briefing days and the peer review week will be fed back into the final report. The assessors are involved in assessing the draft stage of the report before it is finally published. The final report is submitted to the trust, which has to come up with an action plan, which in turn, is overseen by the strategic health authority. Some assessors attend trust action planning days.

Competencies expected from the reviewers are set down by CHI. Assessors are expected to be:
- Good communicators  
- Able to work in teams  
- Analytical and problem solving  
- Task oriented  
- Resilient  
- Organisationally aware

All the mental health service users who have become CHI reviewers agree that it is extremely hard work, but all of them are glad they have taken part and feel that they have really been able to make a difference. The next step is to work with CHI on forensic reviews on secure units, and MIND assessors may be involved in National Service Framework reviews, the inspectorate arm of which will come under the control of CHAI.

Christine O’Connor reminded delegates that the common perception was that the NHS was about structures and institutions, but it was actually about the people who work in it and use it. New approaches should not therefore be about systems, but process. Clinical governance is not about systems; it is a thread running through everything, she said. Knowledge will create informed people, but without an understanding of what the knowledge conveys and provides, it is worthless, she added.
3.6 QUESTIONS AND ANSWERS SESSION
Facilitated by Christine O’Connor, Director, Catch On (Consulting)

CHI assessors
Mike O’Farell, British Acupuncture Council asked how reviewers are accepted by other members of CHI team, and how is the contribution measured?

Ray Davies responded that CHI sends out the reviewers’ details to the trusts under review, and not everyone felt comfortable about this, to begin with, but mostly, the reviewers have been accepted because of the training, which imbues team spirit.

The original questionnaire was badly written, and lacked any real idea of mental health issues. However, with service user input, it has been radically changed and hugely improved. The questionnaire information feeds into the peer review week, and that’s where the contribution can be measured.

Christine O’Connor said this point highlighted the importance of assessors being able to understand what it was they were reviewing. This was still something of a problem for those used in PCT CHI reviews.

Expert patients and their potential for CAM
Anna Dixon, on secondment to the Department of Health asked if there were any wider applications for self efficacy beyond chronic diseases? Kaiser Permanante places more emphasis on self management/care even for patients without long term conditions.

Roy Jones suggested reading Bandura’s book: *Self Efficacy and the Exercise of Control*. He said that Julie Barlow had looked at whether people carry across the ideas of self efficacy into their daily lives, and the results showed that they do.

Bob Sang agreed that the principle could be applied generally. He said that he was working with a PCT in Kent, looking at how this model could be extended across the choice agenda, specifically around the dialogue about referral, opening it up from a narrow ‘consumerist base.’

Peter Smith pointed out that it was difficult to convince people further up the line to accept a fundamental shift, away from demanding consumer, to informed participant. This has implications for citizenship as well. The day all patients are expert patients, the NHS will be a better place, he said.

Michael Fox, chief executive of the Foundation for Integrated Health, commented that the discussion had focused primarily on England, but that there were different arrangements elsewhere in the UK for public participation.

Access to CAM through the health service was a big problem. What single step would be the most useful in that context? For example, is there a route to it, using expert patients/public participation?

There wasn’t any one thing, said Peter Smith. What was required was almost a subversive campaign, using several routes. Self care is being done over the counter which excludes CAM. Everyone could be involved locally, but part of that is knowing how. The Foundation could produce a guide, he suggested.

Bob Sang said it would have to start small because it is very threatening, but he would love to see local citizens involved in business planning, giving them a chance to question some of the built-in assumptions about priorities.

However, people would have to be trained in order to become fully involved, he said. The focus should be on outcomes: how does the population achieve greater mobility and suffer
less pain? for example, and the language should be accessible, not the obfuscation of the financial language preferred by the NHS.

Prof. David Peters, School of Integrated Health, University of Westminster: We have to work with locally appropriate services, and finding users who can help us access CAM will be crucial. We struggle to engage patients in the management of services where they already exist. Thus we have to help people to engage with these new roles. How do we find this new kind of service user? How are we going to create a generation of experts?

Dr Peter Smith said that we were at too early a stage for people to act as drivers. Until recently it had been a very closed shop and difficult for anyone else to get on board. He mentioned that his former health authority had meetings, at which they discussed issues in private, then had an open meeting at which no one else was allowed to ask commissioners questions. Part of the solution lies in making people aware that there are different options open to them to influence the process, he advised.

Roy Jones said that he had learnt some languages ancient and modern, so that he knew about different moods and tenses. He then tried to learn Hebrew, with two tenses and nine moods. That is a paradigm shift - an example of doing something that is about the same material, but in a quite different way, he said. Similarly, the contact a patient has with the service ought to improve their ability to look after themselves and their family.

Bob Sang said that involvement does not happen in the PCT office, but by inviting people to contribute in community settings. There were innovative examples: even the Performance and Planning Framework invited comments from people during “Have your Say Days,” in community and shopping centres. The knock on effect is that it is starting to make managers see that perhaps management also needs to change, he suggested.

Sue Pollit, Therapeutic Services Manager, Big Life Company: The argument used in central Manchester is that communities might want complementary therapies, but the PCT wants to protect their budget. They contend that CAM makes people feel good because it pampers. Therefore just getting people to say what works for them is not necessarily enough.

Christine O'Connor agreed, but said that although PCTs were hailed as the cornerstone of the NHS, the system did not allow them to work as they should. She cited an example of one PCT that had come up with some innovative packages of care for local services, which the acute trust had rejected. This went to arbitration and the STHA found in favour of the acute trust and £3 million was lopped off the primary care budget. The pressure for change is strong, but it is hard to deliver on it because of the stronger pressure to meet targets, she concluded.

What does equity mean?
Mike Cummings, British Medical Acupuncture Society: With the advent of PCTs, great emphasis has been placed on equity of provision. If health services are to be affected by individual patient empowerment, how are we to achieve equity if most of our patients don’t understand the word empowerment, and come to it with a great variety of different personal skills and resources?

Roy Jones said that services are not equally distributed and equity is a very elusive concept. During his work on the English edition of the course manual for the Expert Patients Programme, one of the relevant phrases was: “Becoming a community resource detective.” This suggested that in order to work out the pattern of care for themselves, they needed to know what the community resources were. The key to empowerment is that it is a local experience, developed locally, he said.

Bob Sang commented that contained within the new guidance for patient and public involvement was the need for the NHS itself to become less hard to reach rather than using the “hard to reach groups” label, which was a convenient way of marginalising and displacing people. The Engaging Communities Network was addressing this.
He added that it is also about how GPs choose to practise, so that there is a synthesis of "community activists." What we are not doing is capturing the learning from those social innovations, he warned.

Dr Peter Smith said the term equity had been much overused and abused in the NHS. "It's the tyranny of equitable mediocrity." Too much emphasis in PCTs had been placed on bringing everyone up to the same levels of services even if these were not particularly good, and stopping at that. Striving to do things differently inevitably creates short term inequities, but without them, there will be no progress, and no incentive for others to improve their practice and come up with radical solutions, he said.

Christine O'Connor said that there was a salutary lesson to be learnt from what had happened in education.

Francis Treuherz, Society of Homeopaths emphasised the need for patient support following on from his own experiences of losing his contract after trust status replaced fundholding. Practitioners needed to enlist the help of patients to promote their work within the NHS. Patients do have influence. Equity can mean the lowest common denominator rather than the highest common factor.

Roy Jones commented on recent MRC discussions about research into CAM, at which Professor David Reilly (homeopath) had asked those attending how many of them believed in an innate impulse towards health? "That's the territory between homeopathy and allopathic medicine which we should all be getting into, which goes beyond disputes about the molecules."

Judith Howie, Thames Valley University and International Federation of Aromatherapists argued that complementary practitioners were already using a different approach and empowering users to take control of their health. Yet that was the very thing that CAM practitioners had to defend the most. Would encouraging complementary practitioners and users into the decision making groups not worsen this conflict?

Bob Sang responded that it was an issue of democracy; practitioners could be good and helpful allies to democratise health. It was a difficult struggle, but it was up to practitioners to decide if they wanted to remain in their bubbles.

Health authorities, he said have written out users’ views, but, equally, some CAM therapists have abused their clients, so it was not possible to take the trust for granted. The robustness of accountability underwrites the mutuality of the relationship, and the strength of what’s happening in the system, including the new moves to have users as CHI assessors provides all kinds of new opportunities, he added. “There’s a process of convergence in how we choose to work and learn together in primary care.”

There are different ways of getting into the system and “subverting” the process, but if you are not there, you can’t influence it, said Peter Smith. It also starts to break down some of the barriers. If people with experience of CAM do not get involved in the PCT, it is harder for ideas about it to be accepted.

It is not enough to say ‘We know we’re great, because our patients tell us so.’ We have to be able to demonstrate it. You have to be able to demonstrate it, and that’s where clinical governance is so important. The tools are already there.”

Janice Kent, director Chronic Fatigue Society suggested that the picture painted of the NHS was not one she recognised. She considers herself to be an expert patient, but her referral request was rejected by her GP, on the grounds that she only wanted to see the best, and she was eventually struck off the list. “There are great pitfalls for patients here.” She wondered
whether PPI was all just lip service? “The patient perspective is not that rosy, because the money is not there.”

Bob Sang responded: “You are working in a system that is beset by fear in the management culture, which then gets projected.” In CAM the first two or three sessions are often about drawing out the problems that are rarely or never voiced, and the same skills and sensitivities are needed to create safe environments for managers, he said. It is not easy, but the occupational health statistics for people working inside the NHS speak for themselves. There is a way through, and a lot of CAM practice can be transferred into that environment - if we choose, he said.

Roy Jones said people make active choices to use CAM as part of self management; but the system does not yet widely respect those choices. There is often confusion among conventional practitioners about the disease process and day to day living and health. Pulling those two apart can be very helpful.

Dr Peter Smith urged delegates not to stop getting involved, despite the failures. “If you don’t do it, it won’t happen by itself.”

Christine O’Connor emphasised the need to get involved and pursue the issues, because otherwise things would continue, with the focus on hospital waiting lists and targets, pushing everything else off the agenda.
3.7 WORKSHOP 1: ACHIEVING PATIENT INVOLVEMENT
Facilitated by Christine O’Connor, Director, Catch On (Consulting)

Summary of groupwork and feedback Full feedback in appendix 2

<table>
<thead>
<tr>
<th>Workshop 1: Achieving patient involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How do we get patients involved?</td>
</tr>
<tr>
<td>• Why is it important?</td>
</tr>
<tr>
<td>• How do we find our sponsors/champions?</td>
</tr>
<tr>
<td>• What do we want from them?</td>
</tr>
<tr>
<td>• How will we fulfil the government’s requirements around public involvement?</td>
</tr>
<tr>
<td>• How do we start to bring the strands together into a pathway?</td>
</tr>
<tr>
<td>• Is there a role for expert patients? Is so, what?</td>
</tr>
<tr>
<td>• How can we use patient forums?</td>
</tr>
<tr>
<td>• What do we mean by patient choice? Is it just about where and whether you want your hip replaced?</td>
</tr>
<tr>
<td>• How can we make paradigm shifts happen?</td>
</tr>
</tbody>
</table>

Level and types of patient and public involvement

- Strategic level (PCT & STHAs planning and commissioning - patients, carers and service users can become NEDs, join PCT patient for a)
- At a service level (‘Critical Friends’ groups and service based patient fora) to inform improvements or changes in practice
- Citizen involvement (ad hoc meetings for specific purpose – like jury service – so as to include a broad range not just usual ‘suspects’)
- Via existing participation initiatives (PALS, Patient Fora, NEDs)
- Health panels (e.g. Somerset have groups of 8-10 lay people with a wide range of backgrounds)
- Clinical governance activities (e.g. audit and research including surveys, user groups, feedback processes)
- Developing CAM expert patients
- CAM patient involvement policies need to work within existing involvement structures within the NHS (national and local initiatives)
- Develop a special interest group within the new patient involvement initiative
- Patient involvement needs to relate to the treatment of specific conditions

Encouraging and promoting involvement

- Improve the quality and quantity of information and communication to ensure understanding of how and where they can become involved
- Provide basic expenses to cover the cost of involvement (travel, reimbursement for loss of earnings, child care, free meals)
- Provide information in a range of formats and languages (Braille, translation services, signing)
- School education on involvement initiatives
- Improve patient access to information on CAM (e.g. information on regulation available via NHS Direct
- Quality information on CAM and the NHS needs to be provided (to combat misinformation)
- Information provided on the evidence base for both CAM and orthodox medicine to ensure an integrated approach
A positive dialogue needs to be opened up about choice for patients
Recognise the importance of stakeholder diversity
Be aware of local needs
The barriers between different patient groups need to be addressed
Training for practitioners and managers in inclusive consultation skills
Ensure real ‘partnership’ and not just tokenism
Use plain language not ‘jargon’
Build an education process: e.g. joint, elective workshops on particular condition - with patients, CAM practitioners and GPs
Be aware of patient motivations re involvement (e.g. those who have had positive experiences of CAM, patient with unmet needs)
Be aware of where a patient is on their journey (dependency – empowered) for appropriate level and type of involvement
Address barriers to involvement (e.g. patients may feel they will not be heard, they do not realise they can get involved, fear of change)
Provide information and advice on health service structures and processes (e.g. how a PCT works, and how to participate)
Provide information and advice on consultation and negotiation skills so patients can fully participate in the decision making process

Developing expert patients in relation to CAM
- Development of CAM focused expert patients programme
- Training provided by GPs, PAMs, NHS Managers, expert patient trainers and other existing expert patients
- Develop a ‘patient expert panel’

Role of expert patients (panel) in relation to CAM
- Compel GPs and PCTs to take a more holistic approach
- Impress upon CAM practitioners the importance of NHS services
- Can promote dialogue between orthodox and CAM healthcare professionals
- A panel of patient experts could share experiences of local services (good and bad – CAM and orthodox) with PCT committees

Establishing ‘learning groups’
- Establish learning groups
- Involve GPs, CAM practitioners and patients
- Focus on specific conditions (share experiences – widen understanding)
- Use an established educational process to ensure learning

Development of a CAM strategy group
- Develop a CAM strategy group (for increasing understanding of CAM)
- Provide information on local access to CAM services
- Cross and address barriers between organisations and orthodox and complementary medicine
- Provide information for patients, CAM practitioners and NHS
- Provide information on the CAM evidence base for efficacy and effectiveness
- Provide information on evidence of costs and cost effectiveness
Coordinate patient feedback on CAM (anonymised)
Provide information on clinical governance
Address the issue of equity

Potential CAM champions and sponsors
- Involve patients engaged with involvement initiatives (both local and national e.g. CPPIH, PALS, ‘Critical Friends’ groups, patient fora)
- Involve members of Non Government Organisations
- CAM Networks (IHN, RCCM)
- Involve local interest groups & community and voluntary initiatives (e.g. Health Living Centres, one-stop shops, community centres)
- Patient representative groups [Condition related (e.g. cancer, diabetes, CHD, HIV, arthritis), health related (including well patients, self help & demographic (elderly, mothers and babies, ethnic groups)]
- Practitioner / professional groups with an interest in CAM
- Expert patients and trainers
- Carers

Role and activities appropriate for sponsors and champions
- Attend PCT meetings
- Establish links with patient involvement initiatives
- Have national input (NICE, CHI, Modernisation Agency)
- Have local influence (PEC, NEDs, patient fora, PALS)
- Encourage interest, enthusiasm and ‘buy in’ for CAM NHS services
- Establish links with existing social networks, patient involvement initiatives, community, NGO and voluntary initiatives
- Helping patients ‘get their voices heard’
- Help the process of increasing CAM acceptability (within the NHS)
- Help promote the benefits of CAM primary care provision
- Be able to operate within the framework of orthodox research and management language (including clinical governance)
- Help move the focus away from disease to a more holistic health maintenance approach
- CAM representatives should meet local groups and encourage patient involvement

Other actions necessary and resources needed (open for discussion)
- Create support groups for representatives and champions
- Support patient representatives by providing ‘briefs’ and ‘debriefs’ before and after meetings
- Create panels of GPs and Practitioners to exchange knowledge and experiences around treating specific conditions and to help widen understanding of CAM
- Practitioners could advertise in their clinics to recruit CAM champions and patients to engage in patient and public involvement processes
3.8 WORKSHOP 2: PATIENT OWNERSHIP AND CONCORDANCE CARE PLANS / GOALS FOR EMPOWERMENT

Workshop 2: Patient ownership and concordance care plans/goals for empowerment

- What do we mean by ownership of one’s own health?
- What do we mean by empowerment?
- How might this concept of concordance related to CAM?
- Can we create a template for a care plan for CAM?
- Would we call it a care plan, and what might it contain?
- How do we involve users in the development of personal goals/targets that will keep them motivated?
- How do we create a psychological contract, as a given?
- How will this process help the government’s agenda in terms of public/patient involvement?

Care plan: assessment and referral process

- Diagnosis
- Address the ‘whole person’
- Advice and Information (relevant to condition and treatment options)
- Patient able to discuss personal and/or medical circumstances
- Discussion of the treatment options (including ‘watchful waiting’, lifestyle changes, CAM interventions, referrals for further investigations, medication etc)
- Suitability of specific treatment options discussed with patient
- Discussion of what level of engagement is feasible (including whether they are able to engage with the treatment)
- Discussion of patient preferences
- Discussion of outcomes
- Discussion of patient expectations regarding treatment and outcomes
- Ensure there is a clear understanding of what the treatment entails (including benefits and drawbacks e.g.; outcomes, side effects)
- Agreement drawn up between practitioner and patient signed by both (i.e. within the context of NHS Plan objectives for shared referral letters – rather than just copying referral letters to patients)
- Courses of action advised and refused by the patient should be included in the agreement
- Individual care package appropriate to the condition and situation

Care plan: building in a monitoring and review process

- Treatment reassessed and negotiated with the patient
- Penalties if either side ‘falls down’
- Changes in medication
- Feedback from patients
- Review and evaluate progress (change, timescales, lifestyle changes, changes in medication, referrals to other treatments & investigations)

Care plan: discharge procedure

- Clear discharge policy and procedures (available to patient)
- Aftercare - support (including networks, self-help groups, expert patient programmes, other means for support in the community)
- Continued monitoring of patient progress past treatment period
Contract between patient and service

- Safety (including how that is guaranteed for patient and therapist)
- Therapists’ right to decline treatment (e.g. if inappropriate referral, patients’ with no understanding of what is entailed)
- Patients’ rights (including the right to decline treatment)
- Confidentiality policy and procedures
- Explanation of the process for referral and treatment (including number of sessions, time required)
- Where payments are involved (the costs and methods of payment)
- Complaints and grievance procedures
- Feasible level of engagement expected from the patient
- Cancellation policy (result if patient DNA)
- Clear ‘milestones’ along the way
- Clear accountability framework
- The contract should be renegotiated and develop and over time

Increasing patient involvement and concordance

- Ownership of the process by patients
- Support from NGOs e.g. the King’s Fund, The Prince of Wales’s Foundation for Integrated Health
- As practitioners; listen, act and feedback on the care pathway
- Choice should be informed
- Encourage patients to take more responsibility for their health – with support
- Patients need to be engaged to become involved
- Practitioners need to take a non-judgemental approach
- Inspire patients with the benefits of staying well
- Patient held notes (helps develop understanding)
- Patients need to identify their needs and have access to skilled people to help them

Issues relating to care plans and pathways for future discussion

- Care pathways and plans should address the ‘whole person’, not just the diagnosed condition
- CAM therapies already incorporate ownership and concordance in practice
- Care plans should belong to patients but should be informed and encouraged by practitioners
- Steps of the care pathway must be SMART (Specific, Measurable, Realistic and Timely)
- Individual care packages need to be within the context of teamwork and supervision with multidisciplinary input and training
- Appropriate clinical governance activities need to be in place along the care pathway
- Patients and multidisciplinary healthcare teams all need to be involved in developing care plans
- Care plans should involve patient support groups / charities with regards to specific conditions e.g. diabetes, mental health etc
- Robust materials for commissioning and developing care plans should be developed by CAM related organisations e.g. IHN
Glossary

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>BEST</td>
<td>Broad Evidence Synthesis Topics</td>
</tr>
<tr>
<td>CAM</td>
<td>Complementary and Alternative Medicine</td>
</tr>
<tr>
<td>CHAI</td>
<td>Commission for Health Audit and Inspection</td>
</tr>
<tr>
<td>CHI</td>
<td>Commission for Health Improvement</td>
</tr>
<tr>
<td>CG</td>
<td>Clinical Governance</td>
</tr>
<tr>
<td>CGCAMNET</td>
<td>Clinical Governance for CAM Network</td>
</tr>
<tr>
<td>CP</td>
<td>Complementary Practitioner</td>
</tr>
<tr>
<td>DH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>EBC</td>
<td>Evidence Based Care</td>
</tr>
<tr>
<td>EBM</td>
<td>Evidence Based Medicine</td>
</tr>
<tr>
<td>EBP</td>
<td>Evidence Bases Practice</td>
</tr>
<tr>
<td>GMS</td>
<td>General Medical Services (contract)</td>
</tr>
<tr>
<td>HDPs</td>
<td>Health Delivery Plans</td>
</tr>
<tr>
<td>HIMPs</td>
<td>Health Improvement Plans</td>
</tr>
<tr>
<td>IHN</td>
<td>The Integrated Healthcare Network (<a href="http://www.ihn.org.uk">http://www.ihn.org.uk</a>)</td>
</tr>
<tr>
<td>KF</td>
<td>King’s Fund</td>
</tr>
<tr>
<td>MA</td>
<td>Modernisation Agency</td>
</tr>
<tr>
<td>MCRU</td>
<td>Medical Care Research Unit, University of Sheffield</td>
</tr>
<tr>
<td>MYCAW</td>
<td>Measure Your Concerns and Wellbeing</td>
</tr>
<tr>
<td>MYMOP</td>
<td>Measure Yourself Medical Outcomes Profile</td>
</tr>
<tr>
<td>NAPC</td>
<td>National Association for Primary Care</td>
</tr>
<tr>
<td>NED</td>
<td>Non Executive Director (of PCT)</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Frameworks</td>
</tr>
<tr>
<td>PALS</td>
<td>Patient Advisory and Liaison Services</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td>PCO</td>
<td>Primary Care Organisation</td>
</tr>
<tr>
<td>PEC</td>
<td>Professional Executive Committee (of PCT)</td>
</tr>
<tr>
<td>PI</td>
<td>Performance Indicators</td>
</tr>
<tr>
<td>PMS</td>
<td>Personal Medical Services (contract)</td>
</tr>
<tr>
<td>PoWFIH</td>
<td>Prince of Wales’s Foundation for Integrated Health</td>
</tr>
<tr>
<td>RLHH</td>
<td>Royal London Homeopathic Hospital</td>
</tr>
<tr>
<td>SIH</td>
<td>School of Integrated Health, University of Westminster</td>
</tr>
</tbody>
</table>
Appendix i

List of Participants

Hal Andrews, Clinic Manager, University Clinic, University of Westminster
Kay Barnard, Non-Executive Director, Somerset Coast PCT
Roger Battye, Chairman, National Association for Patient Participation
Ron Bishop, President, British Acupuncture Council
Dr Chris Brian, Complementary Therapy Lead, Canterbury & Coastal PCT
Sally Carr, Director, Citizen Advocacy, Information & Training
Gary Cary, Manager, PALS, Woking area PCT & North Surrey Mental Health Partnership
Kate Cotton, Specialist Projects Leader, Marie Curie Cancer Care
Mathew Cousins, President, British Osteopathic Association
Susan Croft, Director, Consumers For Health Choice
Anthony Davis, Manager, Grove Medical Centre
Léonie Dawson, Professional Adviser (Policy), The Chartered Society of Physiotherapy
Susan Day, RCN Committee Member, Complementary Therapies in Nursing Forum
Michael Dibdin, Chairman, Doctor-Healer Network
Anna Dixon, Strategy Unit Team Member, Department of Health
Judith Draper, Council Member, Craniosacral Therapy Association of UK
Mr Michael Endacott, Director, Institute for Complementary Medicine
Michael Fox, Chief Executive, Prince of Wale’s Foundation for Integrated Health
Roger Goss, Co-Director, Patient Concern
Mel Hatto MBE, Board Chair, Broxtowe & Hucknall PCT
Christopher Head, Chief Executive, Bristol Cancer Help Centre
Denise Hill, Vice Chair, Association of Reflexologists
Liz Hill, PALS Manager, Slough PCT
Dr Judith Howie, Senior Lecturer, Centre for Complementary Therapies (TVU)
Sally Hughes, Project Manager, Regulation, Prince of Wale’s Foundation for Integrated Health
Mary Kearney, Assistant Commissioning Manager, Richmond & Twickenham PCT
Janice Kent, Founder, Remember (The Chronic Fatigue Society)
William Kent, Charity Secretary, Remember (The Chronic Fatigue Society)
Delana Lawson, Kath Locke Centre Manager, The Big Life Company
Ms Vicky Lawson, SMT Manager, Manic Depression Fellowship
Helena Legg, Liaison Health Visitor, Harrow PCT
Sato Liu, Executive Director, Natural Medicines Society
Olwen Long, Non-Executive Director, Guildford & Waverley Primary Care Trust
Freda Magee, Chair, NACTPC
Dr Robin Monro, Director, The Yoga Therapy Centre
Kate Nash, Research Co-ordinator, British School of Osteopathy
Jane Nicholas, Projects Manager, Guildford & Waverley PCT
Dr Charlotte Paterson, Research Fellow, MRC Health Services Research Collaboration
Brenda Peace, Training/ Asssessor/Healer, UK Healers
Sue Politt, Therapeutic Services Manager, The Big Life Company
Dr Pauline Price, General Practitioner, The Fountain Medical Centre
Dr Mohamed Qureshi, GP, Bury PCT
Jane Ramsey, Chair, Lambeth Primary Care Trust
Prof. Nick Read, Chair of Trustees, IBS Network
Kenneth Rock, Vice Chair, British Reflexology Association
Hans G Schrauder, Homeopath Representative, Homeopathic Medical Association
Fiona Sharples, Clinical Audit Manager, The Royal London Homeopathic Hospital
Sue Shattock, Trustee, New Approaches to Cancer
Peter Simmons, Information Manager, Allergy UK
Frances Singer, Co-ordinator & Facilitator of Self Management Training Programme, Manic Depression Fellowship
Efua Taylor, Non Executive Director, Camden PCT
Mike Took, Policy Officer, Rethink
Francis Treuherz, Honorary Secretary, Society of Homeopaths
Maureen Vallon, PALS Manager, Horsham & Chanctonbury
Judy Walker, Co-Director, Help for Health Trust
Sue Ward, Information & Education Manager, National Eczema Society

**Rapporteurs**
Dr Mike Cummings, Medical Director, British Acupuncture Society
Dennis Donnelly, Collaborative Project Co-Ordinator, Liverpool Centre For Health
Dione Hills, Project Manager, Integrated Healthcare, Foundation for Integrated Health
Carol Horner, Non Executive Director, Wycombe PCT
Michael O’Farrell, Chief Executive Officer, British Acupuncture Council
Prof. David Peters, Clinical Director, School of Integrated Health
Prof. Nicky Robinson, Head of Centre for Complementary Therapies, Thames Valley University
Bob Sang, Director, Sang Jacobsson Limited
Appendix ii

Self efficacy academics dealing with Medical Issues and Settings, Clinical issues and Health [www.emory.edu/EDUCATION/mfp/effpage.html](www.emory.edu/EDUCATION/mfp/effpage.html)

Keina Allan (problem-solving skills of adults with chronic psychiatric disorders) - Canada.
Marites Andag (nurses’ SE and terminally ill patients) - University of the Philippines.
Cheryl Beach (SE of physiotherapy students to interact w/older adults) - Surrey, United Kingdom.
Melanie Blackburn (self-efficacy and recovery from mental illness) - Cincinnati.
Deanna Braaksma (nutrition/physical activity in children/parents) - Nova Scotia,
Marilyn Brown (self-efficacy and increased weight-bearing exercise/calcium intake) - Midwestern State.
Donna D. Caruthers (SE and smoking relapse prevention with hospitalized smokers) - Pittsburgh.
Nantiya Chookaew (self-efficacy in HIV reduction) - University of Maryland.
Emely de Vet (role of self-efficacy in organ donation among adolescents) - Netherlands.
Amy Diehl (use of self-efficacy and learned optimism in treatment of PTSD) - Widener University.
Christopher Forju (SE and length of hospital stay for coronary bypass patients) - Cal State University, LA.
Cindy Jennings (children and health education) - University of South Carolina, Spartanburg.
Mary Beth Jennings (SE and aural rehabilitation of older adults) - University of Western Ontario, Canada.
Hyun Sook Kang (SE and exercise adherence in arthritis patients) - South Korea.
Mark Lynch (effects of self-efficacy on clinical research of social work practitioners) - Pittsburgh.
Paula McMullen (SE of RNs participating in post-grad certificate courses) - Australia.
Jyoti Pundlik (self-regulation of Chinese American children with ADHD) - Northeastern University.
Brenda Rea (SE and physical therapists who practice health promotion) - Loma Linda University.
Eka Regina (self-efficacy and obesity) - Atmajaya University, Indonesia.
Victor Robinson (siblings in families w/alcohol problem history) - Northern Ireland.
Samuel Rueda Méndez (SE, health promotion and prevention, drug addiction) - Spain.
Musoke Sande (self-efficacy and condom use among rural youth in Uganda) - Uganda.
Monika Slovínec (self-efficacy and health behaviors) - University of Ottawa, Canada.
Sherri Smith (self-efficacy of hearing use in the elderly) - University of Florida.
Shirley Smith (SE of homeless women in regard to performing the breast self-exam) - Duquesne.
Ana Stipanovic (self-efficacy and diabetes education) - University of Manitoba, Canada.
Wei-Chen Tung (exercise self-efficacy in Taiwan) - Utah.

Attention: BioMedNet has many articles related to the application of self-efficacy in medical settings. Free registration required.
Achieving patient involvement: Workshop 1 groupwork and feedback:

Group 1

Visual analogy: human fertilisation

- Plenty of consumers who want the provision of CAM on the NHS
- Plenty of CAM practitioners who want to be integrated in the NHS.
- Professionals advertise in their clinics, to recruit CAM champions
- Champions go to PCT meetings and form local support groups
- Within the framework of orthodox research and management language, underpinned by clinical governance
- This “fertilises” the NHS

Group 2

Motivations

- May have had a problem with orthodox care
- Positive experience of CAM

However:

- May not want to get involved because they feel they will not be heard/same old system
- Don’t realise they can be involved
- Patients become “institutionalised” by medical system and frightened of change

Roles

- Patients form important bridge between holistic and medicalised view of health
- They exert pressure on doctors to take a more holistic approach but also talk to CAM practitioners about the importance of the NHS

Training

- They need training, partly as expert patients but also in consultation, negotiating skills, so that they can fully participate in decision making process. This should not be delivered by doctors.
- Health care practitioners and managers also need to be trained in inclusive consultation skills

Points of influence

- Find the balance between secondary and primary care, and how far PCT budgets being driven by secondary care. Extend beyond PCTs and aim for Foundation Trusts
- What structures might they influence? NEDs, patient forums, PALS (patient advocacy or advisory?), PCT meetings
- National or local influence? National guidance from NICE, CHI, etc influences local practice, but there is local consultation, so should not be dismissed
- Remember, PCTs are new and evolving, and while patients may not much influence now, that is likely to change

Group 3

1. There are many non-expert patients

- DIY, but people are hindered by the lack of information/communication
- For CAM to be taken seriously, evidence is required
- There has been a lot of research, but it is not acknowledged or accepted by NICE. Regulation may help acceptance process
- Patients ringing NHS Direct can get access to telephone numbers for Institute of Complementary Medicine

2. Listen to the public agenda

- We need to get out to groups and invest in dialogue with them; we could use existing networks, such as Women’s Institute, Lions, Rotary Club, etc.
• Include ad hoc perspective otherwise, the usual suspects will be those getting heard
• Refund travel expenses/reimbursement for lost earning?
• PPI needed at all levels “from margin to the mainstream” to reflect diversity of perspective
• Brief in advance of each meeting, and debrief afterwards, so patients are supported after (as they leave)

3 Find the champions
• Treat their children!
• Sponsors: PCT board/Modernisation Board/patient groups, but for patients to be involved, they would need to be trained.
• Bring in common sense: “the real world will keep us on our ethical toes.”

Group 4

Target it from several different angles
• Health panels are a good way of getting people involved. In Somerset they have them with groups of 8 to 10 people from a wide range of backgrounds, and not just people with chronic illnesses
• Include travel costs/childcare/free meals?
• Facilitate self help groups
• Use one stop shops/community centres/PALS
• School education on PPI and at primary schools (Sir William Wells is trying to get young people involved at school)
• Ask patients how CAM has helped them, and in what way, so we can learn from their experiences and get their voices heard
• Patient satisfaction surveys
• Collect evidence based medicine not only for CAM but also orthodox medicine
• Create champions by involving practitioners already interested in CAM
• Move away from focus on disease, but more holistically to health maintenance
• Be aware of local needs and remember to be accountable

Group 5

Recognise diversity of stakeholders:
• Users and providers come from many different perspectives. Many patients are exploring space by themselves, but many others are wondering how to achieve lift-off; the same is true of GPs

Remove barriers:
• Provide good information about CAM, rather than poor information or misinformation, to tackle prejudice and ignorance
• Open up positive dialogue about choice

Levels of involvement:
• Strategic (PCT/Patient forums/NEDs)
• Funding, commissioning, and meeting local needs with appropriate service provision/therapies
• Personal means empowered patient choice and identifying successful users

Relevance to clinical governance:
• PCTs will have to show they are moving to patient involvement
• Where is patient on personal journey? If at dependency level, requires different input; if into autonomy, expert patients
• Life stage model: many natural processes have been medicalised; these can be reclaimed
Group 6

Key points
- Support overstretched organisations first
- Create a patient panel to share experiences, good and bad, with PCTs and committees
- Create a GP panel with CAM practitioners to share experiences of certain conditions and widen understanding
- Coordinate patient feedback: it is too fragmented at the moment; make sure it is anonymised
- Ensure real partnership rather than tokenism. (No good saying, ‘turn up but do not speak’)
- Relate it to conditions, e.g. migraine, and use PCT language, so less threatening
- Build education process: joint elective workshop on a particular condition, with patients, CAM therapists, and GPs
- Find innovators
- Work with special interest groups, associated with conditions

Caveats:
- Do not see patient involvement as complete answer
- Work with existing structures; no room for anything else
- Make sure the decision makers are on your side. They are at all levels, not just at the top. Without them you will not get anywhere
- Establish trust: without mutual trust, we won’t progress.

Group 7

Why:
- Influence policy with evidence; influence GPs with knowledge
- Audit and research
- Change national policy to include patients

Who:
- Patients but also those who are not sick

When:
- Involve people as early as possible, including school

How:
- Surveys, user groups, feedback boxes in clinics
- Champions from user groups

Group 8

The process is represented visually by:
On the one side:
Spheres of influence, which include:
- Patient forums
- Networks
- PALS
- Media
- PECs
- StHA
- DoH
- Self regulation

On the other:
Diversity, comprising
- Patients with HIV, cancer, arthritis, diabetes, coronary heart disease, etc
- Groups such as the well, the elderly, mothers and babies
The PCT goal is to improve the health of these diverse groups.

They are represented by individuals and collectives:
- Patient groups
- Practitioner groups
- Voluntary groups
- CAM networks
- Local interest groups
- Professional groups
- Non governmental organisations
- Expert patients and trainers
- Carers

All these groups need some form of encouragement. They all have to cross the barriers to get to main spheres of influence.

Barriers and challenges separating the sides:
- Funding
- Information on cost benefit and evidence
- Local information
- Standards
- Training
- Access
- Understanding
- Knowledge
- Attitudes (fear/mistrust)
- Protectionism
- Equity

CAM strategy group could provide information on evidence, effectiveness, and local access and cross the barriers. Users, CAM professionals, NHS would all benefit from this.
Appendix iv

Patient ownership and concordance care plans/goals for empowerment:
Workshop 2 groupwork and feedback

Group 1

Continuing the analogy of human fertilisation:
- Ownership of the process will inform recruitment, so that people who wish to own the process and are motivated will get involved
- Education is vital: robust material for commissioning (ripe endometrium) from CAM organisations, the Web, Integrated Healthcare Network from evidence to influence key players
- They need to be able to talk to key figures who are willing to listen. This in turn will empower and encourage them to continue on the journey. This comes from the Foundation, the King’s Fund, consumer and support groups, professional champions
- This will end in concordance—the mutual agreement of care options with their health providers
- A reborn, integrated NHS

Group 2

Doctor and patient come together:
- Diagnosis, advice, information exchange, with patient talking about circumstances, needs, thoughts on the treatment, etc

Discussion and negotiation of the options:
- Watchful waiting; lifestyle changes; complementary therapies; referral for further investigation; drugs
- Patient feeds in preferences/lifestyle

Agreement drawn up:
- Letter they both sign, in the context of NHS Plan objective for shared referral letters. However, rather than copying referral letter to patient, sharing the original document (and agreeing to it)
- This also covers doctor who recommends a course of action which the patient might have refused

Review process:
- Needs to be built in for further reassessment/negotiation
- Penalties if either side falls down?

Clinical governance:
- Relationship between patient and doctor is the governance wheel, which could help ensure better treatment outcomes and clinical care.
- Main problems: lack of communication

Main problems/issues are usually about communications failures. Process of decentralisation only just getting under way, so large historical legacy to combat.

Group 3

- Informed choice is better than patient choice
- Still a strong need for advocacy with the demise of community health councils
- The terms empowerment and ownership are best replaced by the concept of equal partnership between patient and practitioner, with goals set for first consultation
- Reflective practice is key to training
- Create a contract before diagnosis is made. This should not be too formal, but which could develop over time as trust is built
- Care plans/pathways: if condition not life threatening, try CAM first, but look at person as a whole, not just in terms of diagnosis
- Governance/outcomes: improved quality of life; emotional state
Group 4
- Listen, act, and feedback on the pathway
- Less fragmentation; encourage more transparency
- Choice should be informed
- Empower patient: ask what they want; encourage more self help/care
- Get patients to take more responsibility, but with support
- Patients need to identify their needs and have access to skilled people to help them
- Network/brainstorm
- Trust is vital for this and take an individual approach, rather than lumping people together

Group 5
Ownership:
Taking responsibility and assuming a mutuality in the relationship

Empowerment:
Process of taking responsibility, starting from patient’s own impulse to take action (phone a therapist; explore other options)

Concordance:
Mutual understanding about individual health needs/concerns

Pathway:
1. Assessment process (is patient suitable for a treatment; can they engage with it; what level of engagement feasible);
2. Discussion of outcomes/expectations
3. Tracking patient’s progress around change, timescales, etc.
4. Individual care package appropriate to condition and situation, whereby patient understands their own internal signalling (mental health model of traffic lights: Green need to check; amber it’s getting late; red: gone too far)
   - Clear understanding of what treatment involves; its benefits and drawbacks; and what it proposes to do
5. Evaluate progress
   - Discharge procedure
   - Aftercare, which may include networks and self help groups/other ways for a person to support themselves in the community.
   - Everything must be SMART (Specific, Measured, Appropriate, Realistic, Timely) and celebrate successes
   - Therapists cannot manage individual care package alone; it needs to be within the context of teamwork, supervision, and multidisciplinary input
   - Training is therefore required and group therapy perhaps

The contract in process would include:
- Safety and how that is guaranteed for patient and therapist
- Right to decline therapy
- Explanation of the process/time required/number of sessions
- Patients’ rights
- Complaints and grievance procedures
- Confidentiality
- Cancellation policy: what happens if there is a ‘no show’
- Therapist’s right to decline to treat to protect themselves for inappropriate referral or patient’s lack of understanding about what is entailed
- Pay
- Feasible level of engagement

Clinical governance:
- Evaluation and audit and accountability built in; encourage appropriate referrals and save time and money; encourage informed patient choice; signal training needs

Group 6
Several options:
- Give them their own notes; this creates understanding
- Create a partnership between doctors and themselves to establish agreed goals
- Introduce them to other patients with the same condition and encourage them to get well
All the above can persuade patients to reduce dependency on GPs
- Divide patients into three categories: sick, healthy, unknown.
- Ask healthy patients how they do it and learn from that
- Take advantage of practice nurses/triage nurses, and ask a great deal more of them
- Agenda is broad so focus on two or three key conditions, and create a shared plan for patients with charities heading up these conditions, such as diabetes, migraine, schizophrenia

Caveats
- Do not view patients as conditions, but as people
- Recognise patients might not want to get involved; some people will never want to manage their own health; anticipate the impact on a patient’s life
- Public are cynical about health promotion plans

Group 7
- Ownership of an individual’s body is key
- CAM therapies already incorporate ownership and concordance in practice
- Care plan should belong to patients, but should be informed and encouraged by practitioner
- Care plan is a pathway with milestones
- Patients have to be engaged to become involved: passion and non-judgmental approach is needed and inspiring them with the benefits of staying well

Group 8
A visual analogy of a train travelling towards health along an integrated health care track:
- The train driver is the patient who owns his/her own health in partnership with the carriages of self management and empowerment
- These are fed by information
- The train is fuelled by money attracted by the journey’s destination
- The driver determines his/her own speed
- The train travels along an integrated services track, stopping off at those services required: CAM, community hospital, community services, primary health care team The PCT in the middle is the tree of life, trying to disseminate the health service to people, with the GP as the equivalent of the Fat controller (with apologies to Thomas the Tank Engine)
- Mental health trusts, housing support, acute trusts, voluntary groups, carers, community support groups, social services, and faith groups are on the other side of the track