


# Engaging now

PCTs working with their communities  
to improve services and cut health inequalities



## FOREWORD

The recent command paper Building On The Best – Choice Responsiveness And Equity In The NHS challenged thinking on how the NHS could both promote patient choice and extend equity.

Equity of access has been a principle of the NHS since its inception but as many studies show, despite the role of the NHS in raising standards of health and healthcare, health inequalities have remained and even grown.

What Keep, Sang and Cowper do in this paper is set out how, through local community engagement, PCTs can make a significant contribution to reducing health inequities.

Certainly, it is clear that disadvantaged and deprived sections of communities experience both poorer housing, diet, and health - as well as greater difficulty in obtaining access to health services in an appropriate way.

What the background research to Building On The Best showed, however, was that these people wanted choice as much as any other group and were willing and able to exercise it on their own behalf.

So a key message is that equity is achieved not by treating all patients the same, because all patient are not the same; but by treating them differently.

We need to treat patients as individuals, accommodating their needs and preferences – which will be different from each other. We need a service that can respond to diversity and be flexible in its approach.

The health service can only begin to know and understand the needs of its patients by interacting with its communities and engaging with local people.

This document provides examples of how this is already being done and encourages the debate to take this thinking further. In this paper, as in Building On The Best, PCTs have shown that not only is patient and community engagement possible, but that it has benefits in terms of improved health and health services.

PCTs have a key role in delivering this agenda – working with local stakeholders and through Patient and Public Involvement Forums. Empowering patients and enabling choices for everyone will help conquer the dramatic differences in health inequalities this country faces.

I commend this document, and the work of the National Primary and Care Trust Development programme, to you.

**Harry Cayton**  
Director for Patients  
and the Public,  
Department of Health

**The health service can only begin to know and understand the needs of its patients by interacting with its communities and engaging with local people.**

## CONTENTS

- 4 Helping people to help themselves**
- 6 Chronic disease and the expert patient**
- 8 Patient choice & patient involvement**
- 10 Reconfiguring and redesigning services**
- 12 Communication, communication, communication**
- 14 Strengthening accountability and agencies for change**
- 16 Values**
- 17 Conclusions**
- 18 More about ECLN, The Connectors and Communicating within Communities**

## ACKNOWLEDGEMENTS

This text has been written by Jane Keep, Bob Sang and Andy Cowper.

They, and NatPaCT, would like to thank all their colleagues in PCTs and throughout the NHS, the Modernisation Agency and beyond for their help, inspiration and time.

The credit for this publication is yours, and not ours.

Published by the National Primary and Care Trust Development Programme March 2004

## DISCLAIMER

The views expressed in this document are those of the authors and their colleagues and interviewees herein quoted alone.

## ABOUT 'ENGAGING NOW'

This document aims to help a wider audience understand the strategic importance of community engagement to making reform in the NHS sustainable and to reducing health inequalities.

It is inspired by work that is happening now, in PCTs all over the country. Some are feeling their way into new territory; others have amassed substantial, practical experience of making new kinds of relationships and genuine partnerships between the NHS and the communities they serve. All have been pooling their experience, and reflecting critically upon it, through the Engaging Communities Learning Network (ECLN).

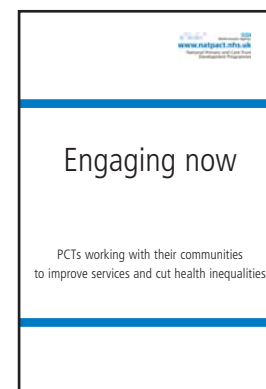
The ECLN has been commissioned by the Modernisation Agency's National Primary and Care Trust Development Programme (NatPaCT). Starting with an initial group of 12 PCT 'learning laboratories' in 2001, it has expanded progressively to include 280 PCTs by February 2004.

The ECLN brings together a dispersed and varied community of practitioners in PCTs, together with strategic health authority leads and partners from the voluntary sector, in order both to support individual PCTs and to consolidate learning.

This publication draws heavily on their contributions to national and regional events and to the web resources of The Connectors and Communicating Within Communities, available at [www.natpact.nhs.uk/engaging\\_communities](http://www.natpact.nhs.uk/engaging_communities).

It has been written by the Network's two independent Facilitators, Jane Keep, regarded as one of the leading practitioners in Health Human Resources Management and Social Partnership, and Bob Sang, who has been leading and facilitating community engagement work for over thirty years.

You can find out more about ECLN on page 18.



# Helping people to help themselves

## HEALTH INEQUALITIES

Health inequalities are the biggest challenges to improving the health of the UK's population.

Research has shown that a man born in Manchester can expect to live, on average, ten years less than one born in Dorset. Babies with fathers in social classes IV and V have a birthweight that is on average 130 grams lower than that of babies with fathers in classes I and II.

Obesity is more prevalent in lower social classes – 28% of women in social class V are obese, compared to 14% in social class I. Women of Bangladeshi origin are less than half as likely as those in the general population to take up invitations to cervical cancer screening.

Mortality from accidents, lung cancer, and coronary heart disease are all higher in men from lower socio-economic groups.

The 1998 Acheson Report was the last major analysis of the social and economic influences on health inequalities in the UK.

## WHAT IS BEING DONE?

Moves to address this situation are under way.

Tackling Health Inequalities: A Programme For Action (launched in the summer of 2003) seeks to achieve the public service agreement target to reduce by 2010 inequalities in health outcomes by 10 per cent as measured by infant mortality and life expectancy at birth. This target is supported by two more detailed objectives:

- starting with children under one year, by 2010 to reduce by at least 10 per cent the gap in mortality between routine and manual groups and the popu-

lation as a whole;

- starting with local authorities, by 2010 to reduce by at least 10 per cent the gap between the fifth of areas with the lowest life expectancy at birth and the population as a whole.

## THE WANLESS REPORTS

In his update report 'Securing Good Health For The Whole Population – Population Health Trends' (2003), Sir Derek Wanless looked at mortality, morbidity, the determinants of health and long-term health drivers.

This work followed on from his funding 'Review for HM Treasury' (2002), in which Wanless proposed three possible scenarios with regard to future health spending needs:

- Slow uptake
- Solid progress
- Fully engaged

The 'fully engaged' scenario implies that "the level of public engagement in relation to health is high, life expectancy goes beyond current forecasts, health status improves dramatically, use of resources is more efficient and the health service is responsive with high rates of technology uptake".

Wanless' financial projections estimate that the difference in cost between the 'slow progress' and 'fully engaged' uptakes would be about £30 billion by 2022-3.

## CHOICE CONSULTATION

In the autumn of 2003, Harry Cayton, the NHS Director for Patients and the Public, was asked to head a consultation into 'Choice, Responsiveness And Equity In The

**“There’s a real hunger to be involved and get things done ... but it doesn’t seem to matter?”** *Joe Devanny, Director*

**FIND OUT MORE:**  
[www.natpact.nhs.uk/engaging\\_communities](http://www.natpact.nhs.uk/engaging_communities)  
[www.dh.gov.uk](http://www.dh.gov.uk)  
[www.hm-treasury.gov.uk/wanless](http://www.hm-treasury.gov.uk/wanless)

NHS And Social Care’.

Reporting in December 2003, this consultation concluded that the NHS needs to:

- carry on building capacity, in particular for people with long-term conditions
- continue the reform of healthcare delivery, including devolving more power to the front line; strengthening local accountability (for example through NHS Foundation Trusts); and introducing new systems to underpin choice such as payment by results
- work at ensuring choices and services genuinely reach everyone, including the most disadvantaged and marginalised groups
- listen to what patients and the public are telling us and then act.

**THE ROLE FOR PCTs – ENCOURAGING LOCAL OWNERSHIP**

PCTs will drive this crucial change: indeed, many are already in the driving seat. This is not just about centralised plans. It is all about localism. As PCTs hold two-thirds of the NHS budget, the responsibility for turning these strategies from rhetoric into reality is firmly in their hands.

Every PCT’s local social and economic factors affect how much there is to be done to close the gaps of health inequalities. Through engagement with their community, PCTs are asking people locally what they want – and crucially, listening to their answers - and beginning to provide a more personal, responsive health service. This offers the best chance of returning a sense of ownership to citizens and communities regarding their health.

**PCTs are asking people what they want.**

Interaction with the most deprived sections of communities will be vital for full engagement. This is a matter of social justice.

PCTs are already developing new mechanisms to talk with and listen to their populations. Through these and other means, they are more openly sharing the responsibility for health with their fellow citizens and patients.

Reports of this progress are being made available to all PCTs on the NatPaCT website through the ‘Engaging Communities Learning Network’ project’s Connectors and Communicating Within Communities sections ([www.natpact.nhs.uk/engagingcommunities](http://www.natpact.nhs.uk/engagingcommunities)).

‘Fully engaged’ is clearly the goal for PCTs. But it isn’t an open goal. To achieve full engagement, the NHS faces the challenges of working differently: of collaborating with patients and citizens to move towards a point where people can challenge and take control of their health needs, and are able

to articulate this at their point of contact with the NHS.

For fifty years, paternalistic traditions in the NHS have confronted patients and citizens with a deep-rooted ‘take-it-or-leave-it’ mentality because care was provided apparently free at the point of use (though in fact paid for through tax).

Those days are over. What is needed now is a new ‘psychological contract’: one which breaks clear from the deep dependency culture and works in partnership with patients and citizens.

Quite simply, this is a new way of looking at health.

**but how do you engage people for whom health service reform**  
*y, Director of Strategy and Partnerships, Reading PCT*

# Chronic disease and the expert patient

Chronic diseases represent around two-thirds of the incidence of ill health in the UK. It is the predominant pattern of disease in this country during the second half of the 20th century and the beginning of the 21st.

Cancer, heart disease, stroke and arthritis can and do kill - but more often they are a burden that people carry from the middle years of their lives into old age.

Moving chronic disease management and self-management further up the priority list is clearly important for PCTs, who may spend up to 80% of their budget on 10% or so of the local patient population.

Poorer people with long-term conditions and disabilities (often complicated by the interaction between two or more diseases, and poor diet or lack of opportunity to exercise) are most likely to use NHS (and related services).

Engagement offers patients the opportunity to step outside the role of 'victims' - to become confident, self-authorised partners in their own health care.

## THE EXPERT PATIENT PROGRAMME

The Expert Patient Programme (EPP) provides opportunities to people who live with long-term chronic conditions to develop new skills to manage their condition better on a day-to-day basis.

It is based on research which shows that people living with chronic illnesses are often in the best position to know what they need in managing their own condition. Provided with the necessary 'self-management' skills, expert patients can make a tangible impact on their disease and quality of life more generally.

## EXAMPLES OF SUCCESS: EXPERT PATIENTS IN PRACTICE

Clearly, Expert Patient Programmes offer highly suitable means to engage with PCT population and to address the challenges of chronic disease.

The Connectors programme has highlighted PCTs'

existing good practice in this area. In Episode Fifteen, Jim Phillips (Principal Trainer for the Expert Patient Programme nationally) indicates that "more than 98% of PCT's are now signed up to the Programme; there are nearly 400 volunteer tutors across the country; and there have been / are 5,000 courses. There have been many successes, including working with traditionally hard-to-reach sectors - such as recovery from substance misuse, mental health issues, and those from deprived areas".

Jim suggests that the key challenges for PCTs are "mainstreaming the EPP into PCTs; getting it high up the PCT agenda so it is no longer an 'add-on'; and understanding how it fits into the overall chronic disease self-management strategic vision. As well as driving this forward into the communities PCT's serve – recruiting more volunteers, and providing more courses".

Episodes 16 and 17 of The Connectors examine the successful work of several PCTs. Reflecting on their experiences, Lesley Baker and Claire Foreman of Southwark PCT highlighted six priorities which they had found to be pre-requisites:

- Using existing structures to take forward Expert Patient Programmes
- Linking with other organisations
- Meeting the needs of local communities
- Presenting the message
- Finding champions and signposts of success
- Satisfied patients spreading the word

Likewise, Marion Gibbon and Siobhan Power of Lewisham PCT's Public and User Involvement Team indicated five crucial factors crucial to success:

- Good publicity through links with voluntary sector and social services
- Good mix of participants
- Commitment by the participants to attend all sessions
- Support group for people who have attended the course

**“The secret to delivering NHS targets? Helping professionals see and help patients help themselves: wins all round.”**

# atient

- Further engagement of attendees in the work of the PCT.

## RESPECTING DIVERSITY

Cultural factors with regard to PCT populations' ethnicity are a crucial element of successful engagement. Cynthia Stone, Patient & Public Involvement Co-ordinator at Ealing PCT, highlights the importance of reaching ethnic minorities, who may not speak English well.

She describes one of the volunteer tutors at Ealing, who speaks seven languages - which is clearly of significant help to their work with the community.

Cath Sisson in Burnley, Pendle and Rossendale PCT is setting up training in the Burnley area to enable volunteers to deliver the Programme in a second language, and looking at cultural issues within this (such as whether the training also could be single gender, and residential).

## WHAT THIS MEANS TO PATIENTS

The Communicating Within Communities series looked at the work of West Norfolk PCT. One Expert Patient interviewed, Siobhan Long, has written about her experiences of the Programme. This is available at the bottom of her interview – as is the good news that Siobhan has gone on to achieve her ambition of returning to work as the new Patients Advisory and Liaison Service Co-ordinator for West Norfolk PCT!

Another Expert Patient from Norfolk, Norman Johnson, defined the personal benefits: "It's about gaining self-confidence and taking control. Those who have completed it are more confident with being able to go up to a health professional and be able to talk to them more. Having the confidence to go to your doctor and talk with them about what you really want done makes a real difference."

He added that he sees the programme as "helping to unburden doctors and suchlike: it emphasises patient power and self-help in the goal of helping them reach targets. It's

about taking the burden off doctors and nurses."

## POTENTIAL CHALLENGES TO THE EXPERT PATIENT PROGRAMME

Both Dr Trish Turner of West Norfolk PCT and Lesley Baker and Claire Foreman of Southwark PCT suggested that one of the main challenges for PCTs is how to win over professional colleagues. They suggest that successful EPP managers ensure that their clinical colleagues have information about the programme, to help them understand what the Programme is (and isn't).

In this way, colleagues can come to see the Programme as something that is helping them; rather than undermining them. Overcoming problems of the title 'Expert Patient' was also found to be an issue for some clinical colleagues, who might feel that it is they (rather than the patient) who is the expert. The need to reach out to different communities and different ages was also recognised, and the implications for capacity issues were noted.

## SUCCESS THROUGH SELF-CARE

Addressing a recent NatPaCT event looking at the US Health Maintenance Organisation Kaiser Permanente's 'self-care' programme for patients with chronic illnesses, David Sobel of Kaiser pointed out that "over 80% of all medical symptoms are self-diagnosed and self-treated without professional care".

He also provided a range of impressive figures on the success of Kaiser's self-care programme. David Sobel's slides from this presentation (which include a range of figures on the gains through successful self-care) are available on the NatPaCT website at [www.natpact.nhs.uk/uploads/DavidSobel.ppt](http://www.natpact.nhs.uk/uploads/DavidSobel.ppt)

This work is more fully explored in Episode 15 of The Connectors.

## FIND OUT MORE:

[www.natpact.nhs.uk/engaging\\_communities](http://www.natpact.nhs.uk/engaging_communities)

[www.expertpatients.nhs.uk](http://www.expertpatients.nhs.uk)

[www.natpact.nhs.uk/uploads/DavidSobel.ppt](http://www.natpact.nhs.uk/uploads/DavidSobel.ppt)

**see it as something that will help them; help them help patients; and."** *Claire Foreman, Public Involvement Manager, Southwark PCT*

# Patient choice and patient involvement

## RISING TO THE CHALLENGES OF CHOICE

From December 2005, patients needing elective surgery will be able to select from at least 4 or 5 different hospitals, again including both NHS and private sector providers.

This choice will be extended to all patients. They will be offered this choice in primary care: at the point the GP refers them to hospital.

This announcement was made mid-way through the Communicating Within Communities interviews. Managers of most of the PCTs involved were asked about their views on the likelihood of their PCT moving successfully to choice (initially at six months waiting). The question was specifically framed around the PCTs' management capacity to handle this development.

Their responses were mixed. One PCT chief executive stated that "The answer at the moment is no, but that's the process we are beginning to get into now". The same PCT's chair voiced a concern that "this is another specific task for which no money is earmarked".

A communications manager pointed out that the capacity to enable choice "will need to be developed over time."

A member of the Patient and Public Involvement committee of one PCT demonstrated a grasp of the challenges ahead regarding choice, in saying, "I think it's laudable but not realistic. Choice may not exist in a very specialist treatment."

## THE DEFINITION OF CHOICE

The definition of choice was raised by one health visitor, who pointed out that "we are already thinking about it – in particular we talked about a definition of what choice means – as there were a variety of experiences

and views about that".

There was also reflection on the public attitude to choice: one PCT's chief executive, who said that "We are going to evaluate this to see what patients think of it, but the early indications are that people like being dealt with individually, and they like being given lots of information and the opportunity to talk their health care through with somebody."

## THE FINE ART OF DOING

Involving all sections of the community is essential to addressing inequalities and to developing patient choice and involvement.

High Peak and Dales PCT Congress of Older People meets regularly to discuss matters relating to health and other services. It provides the opportunity to influence planning and development in the local community, and is facilitated by a Steering Group of mainly older people.

There are over 200 people on High Peak and Dales Congress' database; between 80 and 120 come to each meeting.

The Congress' achievements to date include:

- Influencing the implementation of the Single Assessment Process across North Derbyshire.
- Raising PCT Older Person's Champion awareness of the priority issues for older people and initiating action.
- Influencing the direction of the Social Services Best Value Reviews of both older people's services and residential care.
- Raising the profile and awareness of voluntary services for older people and influencing their strategic direction.
- Specific service improvements, e.g. Sensory Awareness Training for all front-line staff.

**“Enabling people to feel more involved in health care services deliver health services and develop new ones”**

# ement

FIND OUT MORE:

[www.natpact.nhs.uk/engaging\\_communities](http://www.natpact.nhs.uk/engaging_communities)

[www.cppi.org](http://www.cppi.org)

## PATIENT AND PUBLIC INVOLVEMENT FORUMS

More than 570 Patient and Public Involvement Forums started work on 1 December 2003. There is a PPI Forum for each NHS Trust and PCT, and they have extensive new powers to involve the public in health and health-care. Over 4,000 people are involved with PPI Forums throughout England.

The Commission for Patient and Public Involvement in Health is responsible for setting up and supporting PPI Forums. The CPPIH will collect information gathered by the forums, and publish an evaluation of the system of patient and public involvement.

It will also report any concerns on patient safety and welfare to relevant monitoring organisations, such as the Commission for Healthcare Audit and Inspection or the National Patient Safety Agency.

The CPPIH has also launched a consultation on a draft reference guide for PPI Forum members, available on their website.

## A ROLE FOR PALS?

The Patients Advisory and Liaison Service manager of one PCT stated that patient choice "will be done via PALS, as PALS has the current investment with two PALS Workers and a manager. It is envisaged that the patients' choice advisory role will be provided by PALS for choice at six months".

Bernice Cooke, Health Visitor, South Somerset PCT, delivered an optimistic assessment of what choice would represent in service reconfiguration: "It's about enabling people to feel more involved in health care service planning on an equal basis. They should have an equal power base in discussing how we should deliver health services and develop new ones."

**"people like  
being dealt  
with  
individually,  
and they like  
being given  
lots of  
information"**

**ice planning on an equal basis, in discussing how we should  
ones."** *Bernice Cooke, Health Visitor, South Somerset PCT*

# Reconfiguring and redesigning ser

Get it wrong and you can totally lose public confidence ... get it right and you can really harness local support and improve the local NHS".

Keeping the NHS Local – A New Direction of Travel

## NEW LOCALISM

'New localism' has become a mantra of recent public sector reform. Its principle is simple – that more local ownership and delivery of public services will make them more responsive to the service user.

This direction of travel, which began with The NHS Plan in 2000, has been a guiding principle to the devolvement thereafter.

## KEY CHALLENGES IN PRACTICE FOR PCTs

Episode 6 of The Connectors builds on this, suggesting that the key messages for PCTs around service reconfiguration are about:

- developing options for change – with people, not for them
- focusing on re-designing services, not re-locating them
- taking a 'whole system' view.

Now that PCTs are assuming the commissioning role, some of the challenges they are coping with include:

- finding a common language about change in health
- using an accessible, contestable base of evidence and information
- making the time and space to achieve the meaningful dialogues that foster peer-learning
- growing capacity – project management and communications – to support engagement across complex, diverse communities
- commissioning or developing facilitation, internal and external, of the processes / interventions that bring people together to plan, deliver, and evaluate the "participatory design processes".

## THE FRONT LINE OF REDESIGN

This is explored in a case study of recent reconfiguration projects in Medway PCT and Kent and Medway Strategic Health Authority.

Both PCT and Strategic Health Authority colleagues found that local people (patients, carers, and front-line staff) were keen to join the redesign process because they have an immediate sense of what could be improved in the short-term.

Furthermore they found that local people also demonstrated a willingness to contribute to longer-term strategic thinking and envisioning – so much so that some have become involved in producing the documents for wider public consultation.

One of the results of this work was the development of a process model that clarifies the key stages of involvement in service change.

This model has subsequently been shared with the Department of Health's Reconfiguring Hospitals team and the Independent Reconfiguration Panel.

**"Focus groups were developed to represent local people"**

*Paula Turvey, Operational Director*

# ervices

## LIFTING THE STANDARDS

The new Local Improvement Finance Trusts (LIFT), to get private investment to develop primary care premises, offer new opportunities for community engagement.

In Episode 14 of The Connectors, Louise Ramsay (Project Manager, Hull LIFT) describes a variety of approaches used to engage the community in decision-making processes – both at the strategic level and at the design / planning levels.

She points out that while the former are generally well documented, the latter have proved to be more challenging in finding an appropriate balance and in achieving real engagement in a time-constrained process such as LIFT.

The GP practices involved in Hull's LIFT have been encouraged to identify local people (usually patients) to be fully involved within the user groups who have developed the tenants requirements and entered into discussion with the designers regarding room adjacencies and functionality.

The LIFT project in East Hampshire and Fareham & Gosport PCTs is highlighted in their Communicating Within Communities piece. Virginia Wilson-Smith, a Councillor on Havant Borough Council, described how "when they started the consultation, the PCT and Strategic Health Authority have held meetings, and got perspectives from our locally-formed group. And they have taken them on board. The local GPs also have had a very heavy input, as have the hospital staff."

Paula Turvey, Operational Director of East Hampshire PCT also described the way in which their PCT approached this: "focus groups were developed to encompass and represent Emsworth local people's concerns and views, and aspirations for the future."

## FIND OUT MORE:

[www.natpact.nhs.uk/engaging\\_communities](http://www.natpact.nhs.uk/engaging_communities)

[www.dh.gov.uk](http://www.dh.gov.uk)

[www.natpact.nhs.uk/uploads/FV1.doc](http://www.natpact.nhs.uk/uploads/FV1.doc)

**"when they started the consultation, the PCT and Strategic Health Authority got perspectives from our locally-formed group - and they have taken them on board."**

**Virginia Wilson-Smith,  
Councillor, Havant  
Borough Council**

**people's concerns, views, and aspirations for the future."**

**al Director, East Hampshire PCT**

# Communication, communication, communication

PCTs' engagement work clearly requires efforts across a spectrum of kinds of communications with their population. Many colleagues pointed out that in the traditional NHS way of working, communications and community engagement have been seen variously as "box-ticking", "add-ons", "soft stuff", or "not mainstream".

Yet many PCTs already take their communications function more seriously. The penny has dropped that not only do they need to provide good-quality services, they need to make sure that their population understand the services and are consulted about them.

PCTs are also recognising the importance of good internal communications, to ensure that staff are up-to-date and 'on side' with service reconfiguration.

## APPROPRIATE COMMUNICATIONS

In Episode 13 of *The Connectors*, Akhlak Rauf (who works for Bradford Shared Communication Service across all the Bradford PCTs) offered this personal view of the engagement process, with important references to cultural determinants.

"Communication with patients is a vital must for any organisation to be successful in engaging with their patients or service users. However, not all organisations are pro-active in getting to the basics of knowing how communities themselves engage with organisations or their way of communicating. This is particularly true for many of the minority communities that are being failed by organisations who rely on a minority of 'community leaders' or 'spokespersons' to filter information through to grass-roots communities where the real difference needs to be made.

"Once an organisation is ready to challenge its own way of working, then and only then can it truly engage communities in a meaningful manner.

"A number of our initiatives have proven that true

community engagement requires an effort to go out to the communities and build up a relationship of trust before you can expect a real return in how your organisation can make a difference to people's lives.

"These initiatives include running focus groups, organising information and relaxation events, radio work, posters and flyers, producing literature that is in an attractive format with understandable language, organising conferences for communities in their own language requirements.

"PCTs have to be seen to want to engage a truly partnership format rather than simply tick boxes – as many people in communities will tell you."

## CULTURAL AWARENESS

Cultural determinants were also in evidence in the 'introductions' to PCTs interviewed for the *Communicating Within Communities* project.

Each PCT staff member interviewed was asked about the population they served: a composite of these was used as the 'introduction' to each of the main webpages. Staff interviewed displayed impressive knowledge of the socio-demographics of the areas they served, and were clear about the need for their services to be reaching out to all users: not just the 'easy-to-reach' communities.

## INTERNAL AND EXTERNAL INNOVATION

Innovation, too, was evident in much of the communications work of the *Communicating Within Communities* PCTs.

With regard to internal communications, Reading PCT's senior managers at board level went out to the meetings with staff about the PCT's reconfiguration. They also decided to build on their 'protected learning' sessions

**"We found people saying, 'come to us and listen to**

*James Rimmer, Director of Modern*

FIND OUT MORE:

[www.natpact.nhs.uk/  
engaging\\_communities](http://www.natpact.nhs.uk/engaging_communities)

# communication

for staff, of which 10 a year are held at the Madjecki Stadium. The PCT has the first half-hour at these, and one of the 'top triumvirate' (chief executive, chair and the clinical lead) are always there for that session.

Reading's innovations in communicating to their population included having a 'wrap-around' on the free local newspaper, Reading Central – which is delivered to every home.

## WAYS OF LISTENING

James Rimmer, Director of Modernisation at South Somerset PCT, pointed out that the way in which PCTs chose to listen to their population was important. He defined this as "the pre-listening".

South Somerset had set up a series of listening events, initially around specific issues such as community hospital services, and subsequently on an ongoing basis. They focus partly on specific chronic conditions, but also on broad, PCT-wide themes.

He added that "we asked 'how do you want us to listen?' The issues we found were people saying, 'come to us and listen to us, rather than waiting for us to come and talk to you'. We found that specific concerns were raised when we were taking a broad consultative approach."

As a result of these discoveries, South Somerset PCT developed ongoing 'Listening Events'. These were held outside supermarkets, libraries, sports centres, and colleges, and were supported by staff and Non-Executive Directors.

They were held at different times of day, and tried to reach different populations to capture a range of socio-economic categories, so the organisers looked at factors like attending on certain days when there was cheaper shopping.

and they are now very supportive of the changes.

## MIS-HEARING AND TALKING PEOPLE'S LANGUAGE

East Hampshire and Fareham and Gosport PCTs found that problems arose when residents in Emsworth mis-interpreted the nature of local service redesign as part of their LIFT.

The importance of well-chosen language was pointed out by local Councillor Virginia Wilson-Smith: "the consultation used the term 'closed down' about Victoria Cottage Hospital. They are just relocating the beds elsewhere. There was never any intention to pull the Victoria down, it just came out in an unfortunate phrase!"

As a result, a local pressure group was formed to fight the 'closure', and PCT staff attended meetings to more fully explain the plans. The Emsworth residents' focus group is a good example of how initial disquiet has been swung around by the PCT,

and they are now very supportive of the changes.

Councillor Wilson-Smith suggested that another factor was that the facility in question pre-dated the NHS and had been funded by local private subscription, and as such local residents felt greater 'ownership' of the Victoria. As a result of this, they were very protective at the suggestion of change.

She concluded that while local residents understood the changes better after the clarification meetings, "at first they hadn't been clearly told it was not going to be closed".

**"The way in which PCTs chose to listen to their population was important."**

**come to us, rather than waiting for us to come to you'."**

**Modernisation, South Somerset PCT**

# Strengthening accountability and ag

## REFORMS AND TOOLS

In today's NHS, trusts must consult with their local population, and to involve them in their work.

This results from Section 11 of the Health and Social Care Act 2001, which introduced a new duty on the NHS to involve and consult patients and the public in service planning, operation and in the development of proposals for changes.

It is worth noting that involving their population is now a legal obligation for all NHS trusts. It is no longer just an option.

Patient representation on NHS boards or committees has traditionally been vulnerable to a range of problems, ranging from 'going native' (adopting the goals and values of the organisation) to 'special interest group capture' (where an interest group, such as a pressure group for a clinical area or facility, joins the board to influence decision-making in that one aspect).

These problems were exacerbated by the traditional attitude that patient representatives were another 'tick-box' element of service design and delivery: an obligation rather than an inspiration.

## LISTENING TO PATIENTS

Linda Pearson, a Development Facilitator, wrote in to The Connectors project (Episode 11) with the following list of helpful suggestions about how to

translate theories of patient involvement into practice:

- try to let go of the feeling "I know what these people need from me / my department / the NHS", and really listen without interrupting.
- Trust the person / group to work out what they need from service designers / practitioners.
- visit places that are using participatory approaches.
- read around the subject.

**Involving the population is now a legal obligation for all NHS trusts.**

## CPPIH

The establishment of Commission for Public and Patient Involvement in Health in January 2003 was key to this change process. The CPPIH's role is to "work at national, regional and local levels in England to ensure that the voice of both public and patients are heard in health matters".

The CPPIH establishes, funds, monitors and supports Patient and Public Involvement (PPI) Forums and the delivery of the Independent Complaints Advocacy Services (ICAS). It appoints all the members to PPI Forums and offers guidance and support to PPI Forums and ICAS.

The CPPIH is responsible for reporting to and advising the Government on how the PPI system is functioning. It liaises with Commission for Health Inspection and Audit (CHAI) on patient and public involvement issues, and makes recommendations to CHAI and the

**“The secret to delivering NHS targets? Helping professionals see and help patients help themselves: wins all round**

# agencies for change

Department of Health.

## CHAI

In April 2004, the Commission for Healthcare Audit and Inspection will come out of the shadows and become established as the successor to the Commission for Health Improvement.

The new CHAI will assume responsibility for the 'star ratings' of NHS trusts. In assessing PCTs, CHAI will consider trusts' records on public and patient engagement and involvement. Its Chair, Professor Sir Ian Kennedy, has repeatedly stressed that CHAI is a new organisation, and will seek to help trusts rather than to point fingers.

However, PCTs (like all NHS trusts) would be advised to note that new CHAI's very name suggests (in 'Audit and Inspection', unlike the 'Improvement' of its predecessor CHI) that it will seek a methodology of assessing trusts' performance across the board.

Professor Kennedy's conclusions in his report on the Bristol Royal Infirmary cardiac services for children show that he recognises the crucial importance of 'Public involvement through empowerment' (sections 157 through to 166). These are well worth the re-reading by any health care professional. Kennedy explicitly states that "The involvement of the public in the NHS must be embedded in its structures."

## MEASURING THINGS THAT MATTER

Dr Sian Griffiths, President of the Faculty of Public Health, wrote in Episode 18 of The Connectors that "the importance of PCTs working with local authorities is key, as is the regular monitoring of progress through performance management".

## FIND OUT MORE:

[www.fphm.org.uk](http://www.fphm.org.uk)  
[www.dh.gov.uk](http://www.dh.gov.uk)  
[www.cppih.org](http://www.cppih.org)  
[www.chai.org.uk](http://www.chai.org.uk)  
[www.bristol-inquiry.org.uk/finalreport](http://www.bristol-inquiry.org.uk/finalreport)

**"Try to let go  
of the feeling  
'I know what these  
people need from  
me, my department  
or from the NHS'  
- and really listen  
without interrupting."**

**Linda Pearson,**

**Development Facilitator**

**see it as something that will help them; help them help patients;  
and." Claire Foreman, Public Involvement Manager, Southwark PCT**

# Values

## THE NEW LOCALISM

PCTs and foundation hospitals are both creations of the policies intended to bring about a more locally engaged and rooted NHS. The first wave of foundation status applications are currently going through the final stages, and will come into full being on 1st April 2004.

## PCTs' OWN VALUES

South Somerset PCT was chosen for the Communicating Within Communities series to highlight its work in communicating its own purpose, role, responsibilities and values of a PCT.

Chief Executive Virginia Pearson implied that there were two value-sets as a PCT: the national (NSFs, targets, etc) and the local, saying " There are nationally-defined roles for any PCT, but the values and culture of the organisation and the staff are something we lead locally. Our values partly derive from how members of the PCT board feel about what we should do, and how we should do it and these values are strongly held by our staff."

She also indicated that she felt engagement was a core value, when she defined successful community involvement as being "about a completely shared vision between ourselves and all partner agencies (particularly the district council) which reflected local needs and desires about service provision".

However, Mrs Margaret Willy, a service user and non-executive director of South Somerset PCT provided a cautionary note. In her interview, she gave her definition of successful engagement of the population as "The knowledge of where to go and whom to see when a problem occurs, and thereby to achieve a resolution. It should help people to be aware of what is available. It is a very new concept. And this is not something the NHS traditionally does at all well."

**"values and culture .**

**Virginia Pearson**

**Chief Executive, South Somerset PCT**

**"Trust me, I'm  
should be a guide  
of this new a**

**Dr John Reid MP, Secretary**

**Speech to the New Health N**

**Unless and until PCTs are in a posit  
Wanless' goal of a self-sustaining nation**

... we lead locally”

Pearson,

South Somerset PCT

“I’m a patient  
guiding principle  
new agenda.”

Secretary of State for Health

Health Network, 15th July 2003

## Conclusions

The work of the Engaging Communities Learning Network has shown that PCTs across the country are already engaging their communities.

This is not another central initiative about prescribing what NHS should do. Rather, its success has been about listening, sharing and finding local ‘bottom-up’ solutions through networks and trust. We very much hope that this richness finds its way into the current public health consultation.

There is plenty of exciting and innovative work going on – more than we can reflect here. Yet much more remains to be done, and we would welcome hearing from you about your experiences and lessons. To get in touch with us, or indeed if you would like to join the ECLN, please contact Kathie Andrews, Programme Administrator, by e-mail at [natpact@hfht.org](mailto:natpact@hfht.org) (or telephone 01962 872201, or fax 01962 831901).

The business imperative is now clear. Unless and until PCTs are in a position to enable mutual engagement in the three key domains of governance, public health stewardship, and services improvement that they both commission and provide, Wanless’ goal of a self-sustaining national health system will not be realised.

Clearly it makes sound financial sense (as well as personal and social sense) for everybody – patients, citizens, PCTs and the wider NHS to make engagement a top priority. The costs - and opportunity costs - of prioritising engagement to cut inequalities may be high. Yet the NHS cannot afford to fail in making engagement with the communities and citizens it serves a greater part of its business.

... position to enable mutual engagement,  
... national health service will not be realised.

## THE ENGAGING COMMUNITIES LEARNING NETWORK

Engaging Communities Learning Network (ECLN) for PCTs was commissioned by NatPaCT in 2001 as a response to the twin policy drivers of patient and public involvement in health and the social partnership with staff.

Its overall aim is to enable PCTs to demonstrate that through patient and public involvement, they have improved (through working on local and national targets (and their in-trays) control of demand (upstream) and service performance (downstream) while building local confidence and their stewardship role

Starting with an initial group of 12 PCT 'learning laboratories', the ECLN has expanded progressively to include 280-plus PCTs by the end of 2003/4

ECLN has taken a "Learning Network" as a means of developing and sharing knowledge across a dispersed community of practitioners. In the case of ECLN, these practitioners are PCT colleagues who carry responsibility for implementing the above policies and legislation, often working with partners from the voluntary sector and with their strategic health authority leads.

The 'architecture' of the network reflects the need to link policy and practice to wider global knowledge and to networks concerned with community engagement, as the figure at the foot of this page shows:

In practical terms what the ECLN has done is to

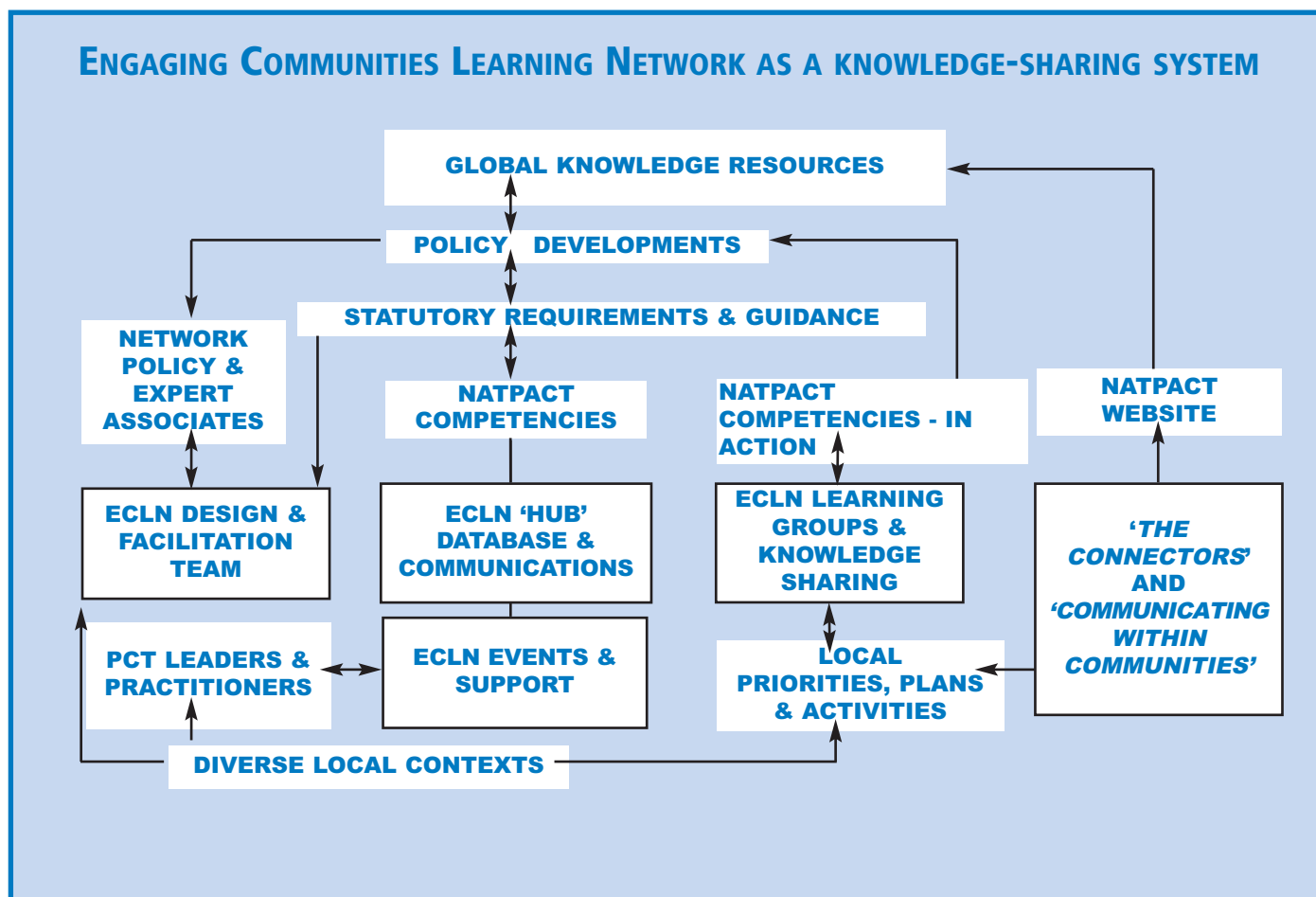
- Support enable and share innovative, often pioneering,

work of PCTs themselves.

- Provide an administrative and communications infrastructure provided by NatPaCT through the dedicated 'Engaging Communities' office: the "ECLN hub".
- Offer a series of interventions including a series of national working conferences, often involving policy 'leads' from the Department of Health, and national workshops; and field support by the project facilitators, entailing both local site visits to focus on specific challenges, and regional workshops to enable peer learning among PCT "leads".
- Develop a knowledge management system (learning materials, and real case material from PCTs) that will sustain the network beyond the project timeframe, working in collaboration with colleagues across the Modernisation Agency.

Everything the ECLN team does is an intervention that can be 'designed in' and 'reflected upon' in order both to support individual PCTs and to consolidate learning through national and regional events and through The Connectors - an experimental learning resource for all those who want to facilitate the effective involvement of local people in health and health services improvement.)

Increasingly, colleagues from PCTs have been involved in the design to implementation to dissemination process. When the ECLN was commissioned by NatPaCT, its two independent facilitators, Jane Keep and Bob Sang, pooled their complementary resources and experience to develop the design described above.



**Jane Keep** is regarded as one of the leading practitioners in strategic change & human resources, and social partnership. She has worked at a senior level in the NHS in HR and in Organisational Development, and is also very experienced in Policy Development at the highest level. As such, Jane works from "Inside Out", enabling the culture changes that are implied by the new policy agenda and NHS modernisation.

**Bob Sang** has been leading and facilitating community engagement work for over thirty years, working principally from the perspectives of community action, citizen advocacy, and patient and public involvement in health decision-making. He works from "Outside In", influencing and facilitating change at every level: from day-to-day practice in service settings, to the commissioning of major change, and into policy development nationally.

Jane and Bob have acted as writers and editors for The Connectors, and for the many reports produced through ECLN events and activities. The evolution of ECLN and The Connectors has reflected the rapid growth in the importance and significance of the community engagement agenda over the past two years.

An interesting 'flow chart' emerges (shown below), which is reflected in the structure of this document

By capturing the learning from national events and activities, and by relating policy change and performance priorities to local implementation, The Connectors has offered a virtual space for capturing and synthesising policy updates, critical reviews, and PCTs' learning from the field. Thus, the ECLN has endeavoured to capture key aspects of the 'journey' described in the above flow diagram, culminating in PCTs' greatest challenge – leading the attainment of Wanless' "fully engaged" scenario.

This publication sets out to engage you in engaging communities, through sharing real cases, issues and challenges of the key policy changes via the learning so far from PCTs and other colleagues in the NHS at the practice interface.

You will have found throughout this publication references to key policy documents, websites of interest, and real case studies and quotes from PCTs working within the 'thick' of this policy-to-practice interface. We have quoted from practitioners here to continue to build the vast amount of practitioner knowledge and case history in this growing field.

The ECLN's journey continues, with innovative and emergent strategies. We invite you to share your views

If you would like to join the ECLN, please contact Kathie Andrews, Programme Administrator at [natpact@hfht.org](mailto:natpact@hfht.org), telephone 01962 872201, or fax 01962 831901.

## THE CONNECTORS

The Connectors is the first of its kind. It aims to challenge thinking, support innovative practice, and reflect on the values that sustain an inclusive participatory culture across the NHS and the diverse communities it serves. The Connectors stories and resources are available on NatPaCT's website, at: [www.natpact.nhs.uk/engaging\\_communities/the\\_connectors](http://www.natpact.nhs.uk/engaging_communities/the_connectors)

## COMMUNICATING WITHIN COMMUNITIES

The Communicating Within Communities project was commissioned by the ECLN in the summer of 2003.

They appointed Andy Cowper (a journalist specialising in health care management) to interview staff, patients and stakeholders at several PCTs.

This project was designed to show how these PCTs were working with their communities in bringing about key changes in primary care, with emphasis on how these changes were being communicated to the PCT population.

The PCTs and subject areas were:

**Reading PCT** - community involvement in major service reconfiguration

**West Norfolk PCT** - the development, purposes and implementation of expert patient programmes

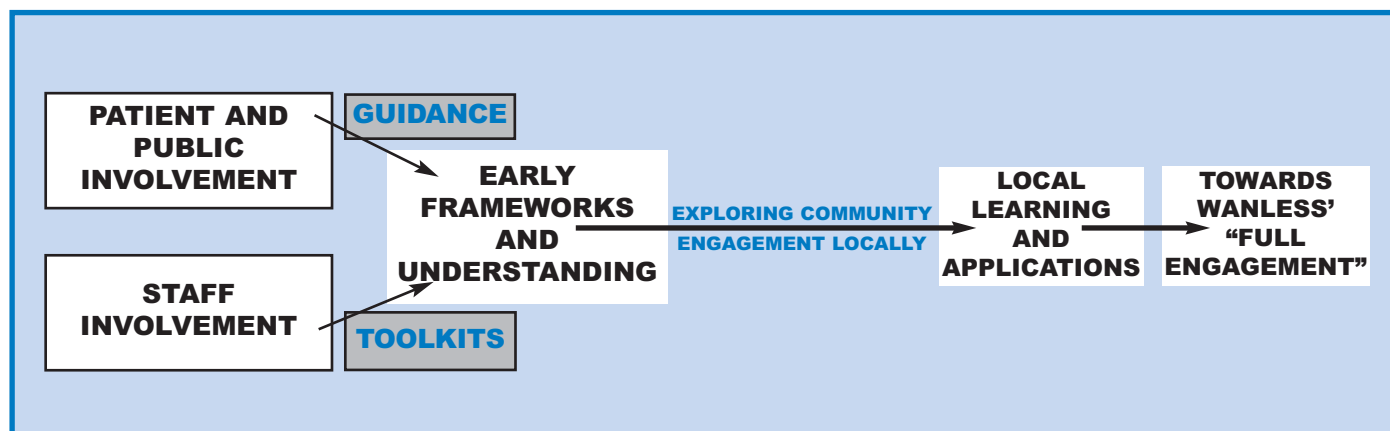
**East Hampshire PCT and Fareham and Gosport PCT** - PCT investment programmes such as LIFT

**South Somerset PCT** - purpose, role, responsibilities and values of their PCT

**Eastern Leicester PCT and Leicester City West PCT** - the development, availability and purposes of Patient Advice and Liaison Services

These interviews are available on NatPaCT's website, at:

[www.natpact.nhs.uk/engaging\\_communities/communicating\\_within\\_communities](http://www.natpact.nhs.uk/engaging_communities/communicating_within_communities)





Engaging Communities Learning Network  
Highcroft  
Help for Health Trust  
Romsey Road  
Winchester  
Hampshire SO22 5DH  
Tel 01962 872201  
Fax 01962 831901  
email natpact@hfht.org

National Primary and Care Trust Development Programme  
Blenheim House  
West One  
Duncombe Street  
Leeds LS1 4PL  
tel 0113 254 3800  
fax 0113 254 3809  
email natpact@doh.gsi.gov.uk  
www.natpact.nhs.uk